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ABSTRACT

This conference proceedings reports on a 1989 meeting addressing respite care for families of children with mental, emotional or behavioral disorders. The conference addressed: (1) respite care concepts, programs, and issues; and (2) planning for designing, financing, and implementing state and local respite programs. The report contains the conference agenda, transcriptions of speeches and panel presentations with a biographical sketch of each speaker, state delegation worksheets, specific state delegation work session plans, a list of workshop participants, and conference evaluation responses. Concerns addressed in workshops included how to finance respite care services, how to best train respite care providers, how to pull together diverse elements in a community to advocate for respite care services, and how to actually design and implement a program. State delegations generated action plans including efforts to coordinate various interest groups, to raise the awareness in local communities, to develop advisory boards, to collect data, to lobby state legislatures for funds and reasonable standards, and to identify needs of parents. (DB)

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RESPITE CARE:
A KEY INGREDIENT OF FAMILY SUPPORT

Sponsored by: Research and Training Center on Family Support
and Children's Mental Health
Portland State University

In collaboration with CASSP projects in
Indiana
Illinois
Kansas
Kentucky
Ohio
Oklahoma
West Virginia and
Wisconsin

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INTRODUCTION

The *Respite Care: A Key Ingredient of Family Support* conference was held in Covington, Kentucky, on October 28-30, 1989. The mission of the conference was to present information on respite care to families of children who have mental, emotional, or behavioral disorders and to professionals who work with these families.

CONFERENCE OBJECTIVES

The primary objectives of the Respite Care Conference were: (1) to provide participants with information about respite care concepts, programs, and issues; and (2) to help participants develop plans for designing, financing, and implementing respite programs in their states and communities. In addition, the conference was viewed as an opportunity to add to the base of knowledge about respite care especially for this population of families and children, while learning and incorporating information from existing programs developed for families of children who have other disabilities.

The conference was designed to promote collaboration between families and professionals. The format of the conference provided opportunities for participants to identify issues and barriers related to establishing respite care programs, for parents and professionals from different states to share experiences, and for state parent-professional delegations to develop plans for implementing ideas in their respective states and communities so that the needs of children who have mental, emotional, and behavioral disorders and their families may be better met.

PARTICIPANTS

The conference involved equal numbers of parents and professionals from around the country. It was planned that most participants would attend as members of state delegations. These delegations were organized through the state mental health program in many states. Limited space was available for individuals who wished to attend from states that did not send delegations.

While the composition of each state delegation varied, our goal was to assemble delegations that would be composed of: (1) policy-making, administrative and service delivery professionals from the major public systems that serve children and youth who have emotional problems; (2) service providers; (3) families of children who have emotional disorders; and (4) people who have developed and implemented respite care programs both for this population and for families of children with other disabilities.

We relied upon the assistance of each state's mental health program, either through their Child and Adolescent Service System Program (CASSP) or State Mental Health Representatives for Children and Youth (SMHRCY) representative, to assemble the state delegations. Research and Training Center staff connected individuals who were interested in attending with state coordinators when applicable. To ensure that the greatest number of parents who were interested could attend the conference, a limited number of parent scholarships were offered which covered travel, lodging, meals, conference fees, and child care reimbursement.

In addition to registered conference attendees, participants included speakers, panel members and workshop leaders with expertise and experience in the area of respite care and family support. Approximately 190 people participated in the two-day meeting, including Research and Training center staff. Approximately thirty-six states were represented at the conference. About 40 percent of those in attendance were family members.

SPONSORSHIP

The conference was sponsored by the Research and Training Center on Family Support and Children's Mental Health at Portland State University in Portland, Oregon, in collaboration with CASSP projects in Indiana, Illinois, Kansas, Kentucky, Ohio, Oklahoma, West Virginia, and Wisconsin. The conference hosts were the CASSP programs in Kentucky and Ohio.

The Research and Training Center was established October 1, 1984, through funding from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and the National Institute of Mental Health (NIMH), U.S. Department of Health and Human Services. The Center was funded for a second five years on October 1, 1989. The focus of the center during this second five-year period is upon families of children who have mental, emotional, or behavioral disorders. The Respite Care Conference is a natural outgrowth of the Center's work in this area. The Research and Training Center is affiliated with the Regional Research Institute for Human Services, Graduate School of Social Work, Portland State University.

The Child and Adolescent Service System Program (CASSP) was launched by the National Institute of Mental Health (NIMH) in 1984 to address the needs of children and adolescents who have severe emotional disorders. The program is designed to assist states and communities to improve systems of care for this population. The philosophy of CASSP is that children should receive community-based care if at all possible; should enjoy family involvement in the design and delivery of services; should receive culturally competent services; and should have flexible, comprehensive systems of care established across agencies within states and communities.

CONFERENCE PROCEEDINGS

These conference proceedings include: (1) the conference agenda; (2) transcriptions of speeches and panel presentations as well as a biographical sketch of each speaker; (3) state delegation worksheets; (4) specific state delegation work session plans; (5) a list of workshop presenters, panelists, moderators, and speakers; and (6) conference evaluation responses.

We hope that the conference experience will be an impetus for further development of respite care services for families of children who have emotional problems. We believe the conference proceedings will be useful to those interested in increasing respite care services and family supports in states and local communities. We extend our sincere appreciation to all conference participants. Their contributions and enthusiasm will help translate the concepts of family support and respite care into reality for children and families across the country.

RESPITE CARE: A KEY INGREDIENT OF FAMILY SUPPORT
AGENDA

Saturday, October 28, 1989

6:00-8:00 Registration and Refreshments--Indoor Pool Area

Sunday, October 29, 1989

8:45-9:00 Introductions & Welcome--Canterbury Room
Barbara Friesen & Catherine Staib

9:00-10:15 **Plenary Panel: Respite Care: A Key Ingredient of Family Support--Canterbury Room**

Terry Butler, Barbara Huff, Creasa Reed, and Judith Sturtevant
Moderator: Ellen Kagen

10:30-12:00 **Workshops (Choose one)**

A-1 "Natural Allies" Respite and Parent Support Groups--Dover Room
Joyce Aaron and Meredith Adler

A-2 Mental Health Family Respite Care - A Model Project--Ivanhoe Room
Milton Cassady and Elizabeth Newhouse

A-3 Respite is a Family Matter--Beowulf Room
Louise Barnes, Wade McCurdy, Matthew Timm, and Carol Chatman

B-1 Rest A Bit: Respite Care Training for Families of Children with Emotional Problems--Grendel Room
Richard Donner and Barbara Huff

B-2 Why Re-Invent the Wheel? How to Preview and Select Instructional Materials, To Adopt or Adapt, that will Meet Your Training Needs--New Castle Room
Phyllis Tarrant

C-1 Financing Respite Services--Woden Room
Ted Boyden and Bill Underwood

D-1 Building Advocacy for Respite Care: The Maine Model--Oxford Room
Susan Failing

D-2 Parents Creating Respite Services--Bedford Room
Judith Wagner

12:00-1:30 **Luncheon Address: Enhancing Treatment for Children and Families Through Provision of Respite Services--**
Canterbury Room
Richard Donner

1:45-3:15 Workshops (Choose one)

A-4 Halcyon Respite--Beowulf Room
Thalia Forist and David Jinkins

A-5 Rural Respite Care: From Model to Program--Bedford Room
J. Michael Geary and David Majic

A-6 "The Break Away" Respite Program--New Castle Room
Creasa Reed and Melissa Runyan

A-7 The Vermont Respite Care Demonstration Project--Westminster Room
Judith Sturtevant and Mary Carol Masseneau

B-3 Rest A Bit: Respite Care Training for Families of Children with Emotional Problems--Grendel Room
Richard Donner and Barbara Huff
(repeat of morning workshop)

B-4 Training for Respite Care Providers--Dover Room
Joyce Aaron

C-2 Financing Respite Services--Woden Room
Ted Boyden and Bill Underwood
(repeat of morning workshop)

D-3 Building Advocacy for Respite Care: The Maine Model--Oxford Room
Susan Failing
(repeat of morning workshop)

D-4 How to Start a Respite Program--Ivanhoe Room
Milton Cassady and Elizabeth Newhouse

3:30-5:00 State Delegation Work Sessions

5:30-6:30 Resource Exchange and Refreshments--Canterbury Room

Monday, October 30, 1989

8:00-8:30 Continental Breakfast--Canterbury Room

8:30-10:00 Plenary Panel: Respite Care: The National Perspective--Canterbury Room

Ted Boyden, Milton Cassady, and Elizabeth Newhouse
Moderator: William Scott

10:15-11:45 State Delegation Work Sessions

12:00-1:30 Luncheon and Closing Session--Stuart Room

October 29, 1989

A.M.

BARBARA FRIESEN:

Barbara Friesen is the Director of the Research and Training Center on Family Support and Children's Mental Health at Portland State University. She is also a professor at the Graduate School of Social Work at Portland State. Dr. Friesen proposed and developed the Families as Allies Project during the last five years and has been instrumental in advocating for families whose children have emotional or behavioral problems. She is especially committed to the concepts of family support and community-based services for families.

Hello, I'm Barbara Friesen from the Portland Research and Training Center and it is my great pleasure to welcome you to what may be the first *annual* respite conference. In addition to the Research and Training Center, two states, Kentucky and Ohio are acting as hosts for this conference and they both have been very helpful in getting things put together. Especially, I want to mention Creasa Reed and Linda Beebe from Kentucky. And Linda is one of the two people at this conference that has a little tag that says VIP and that means that she is one of the two people who can make things happen. If you want anything different to happen, you have to find Linda. The other person, who is from the Portland Research and Training Center, is Katie Yoakum. She is the other person who has the VIP tag and she can also make things happen. Without Linda and Katie I don't think this conference would have happened; Linda and Katie really did the day-to-day organization work. You may have talked to them on the phone and sent them things in the mail.

This conference has been at least three years in the making, as they say in Hollywood. More than two years ago a group of us who had been talking for some time about the need for respite services, especially for families whose children have serious emotional or behavioral disorders, met in Kansas City to talk about putting a respite conference together. We knew that respite services are a very important part of a larger package of family support services. We also knew that the need for respite service was very high, especially for families whose children have emotional disorders. Many years ago when I worked in a day treatment program with families and children who had emotional disorders, I remember staff, and I was one of them, who would sit and talk to each other about what a sad thing it was that there were families who for years had not been out together to a movie or had been able to leave for a weekend. We didn't quite see that that was our problem. Things have changed now. I think most of us in the mental health field, in the field of child welfare, in juvenile justice, and education see that family support services, including respite care, are very central to helping children learn to grow and develop.

Those of us planning the conference also knew that in addition to the importance of respite services, this was kind of ground-breaking because since there weren't very many respite services in the country, there wasn't a whole bank of experts we could call on. So we looked at ourselves and gazed at our navels a little bit and said, "If anybody is going to put this together, I guess we are going to have to." We asked ourselves some questions. First we said, "Do you really think there is enough interest in respite services to have a whole conference just on respite services?" We decided that there probably was and if there wasn't, there should be and we could stir some up. The second thing we asked ourselves was whether there was enough information and expertise to have a whole conference on respite services, especially focused on families whose children have emotional disorders. Again, we said, "Well, we knew that there were some things developing and we could dig around and find them." We knew that we were going to have to make some of it up.

So this is a conference in the very real sense of the word which is that there are people here who will be giving speeches and people here who will be doing workshops and giving formal presentations, but it is also a conference in the sense of a coming of people to confer together, people who have mutual interests and have expertise to share. We know that parents who are here know what they need, and we know that respite providers who are here know what it takes to make this happen. There are other people here who are representatives of a variety of mental health, child welfare, human services and you know more about the systems in your states and what it would take to really get respite services to be a central part of what goes on in your state. So we all come here with different information. Part of your goal here is to listen and learn, but also, if you look at the agenda, you will see that part of what you are going to do is to work. This afternoon from 3:30 to 5:00 people from various states will be in working groups. If you look at your name tags it says what your workshops are and on the bottom of your name tag it says group number and a room and that is the state delegation group with which you will meet. If you don't know, if you have lost your name tag and don't know what those are, come to one of us. Some of you come from states that have only a couple of people here. There is a very brave woman here from Arizona and she is alone. So those of you who come from states like that, we have clumped you together and you can work with other people who are here from states with one or two people per state.

It is my pleasure now to introduce Catherine Staib whom I met on my last trip to Kentucky. Catherine is a lot of things as she will tell you, but one of the things which she says about herself in addition to being a parent, is that she is the liquor lawyer for Kentucky. I like that alliteration. So without further ado I introduce you to Catherine Staib.

CATHERINE STAIB:

Catherine Staib is an attorney working for the State of Kentucky's Liquor Control Commission. She is the parent of an 18 year old daughter who has a mental health disability.

Thank you very much. If there are a few consumers of liquor out there in the audience, we encourage that within reason. I remember very, very clearly the first time I heard the word respite. My daughter had been ill with schizophrenia for maybe three years, and I was asked to join a committee that CASSP was sponsoring to draw up a service system. I went to the first meeting because I was going to be the only parent there, full of arrogance and perhaps thought, "What do these people know about my situation?" I got to the meeting and one of the words I kept hearing was respite. I didn't know what they were talking about but finally it dawned on me. I realized that they were talking about something that I really felt a need for. My mother was the respite giver in my family. It was a relief to know that professionals recognized the need for respite and that it wasn't abnormal, there was nothing wrong with wanting to get away from your child for awhile. It was OK! Surveys of parents and the needs they have in dealing with their emotionally disturbed children consistently find respite high on the list of needs. Respite is the pressure valve in the family, it is the reliever of stress from 24-hour care that a lot of parents have to give their children. I think it is the family's link with sanity, their opportunity to regroup, whether we are talking about a couple of hours in a day or a full day or a weekend, this gives the family the opportunity to have some oneness. In a two-parent family it gives them the opportunity to keep that family together. I think that anything we do that helps parents cope with the situation also helps the children. I think emotionally disturbed children do much better if their parents aren't emotionally disturbed. That's what respite is. It is exciting to me that a word that was alien and foreign to me just a few years ago is important enough to bring so many people together into a conference such as this one. A conference can make respite a reality in our states--even if it is just a state with one representative here--make respite a reality. On behalf of the Commonwealth of Kentucky, a wonderful place to take a respite, I might add, I welcome you to our state and I hope a lot of you have an opportunity to explore some of the things we have to offer. I hope that you will come back again and enjoy the Bluegrass area and other areas of the state, including "Looeyville", and I wish you a very good and productive session.

BARBARA FRIESEN:

Now it is my pleasure to introduce one who was very much a central part of the thinking and planning for this conference. Bill Scott used to be the director of the Child and Adolescent Service System Program in Kentucky and he became what, in Revolutionary War times, was called a turncoat and in Civil War times was called a carpetbagger, and he has now taken himself off to New York. We thought long and hard about whether to let him come to this conference or not (this is a joke), but we decided to have him come. Seriously, Bill was very instrumental to this national conference and I am very pleased to introduce him as the moderator of the opening panel.

BILL SCOTT:

Bill Scott currently is employed at the Ontario County Department of Mental Health, Canandaiqua, New York. Before moving to New York State, Bill Scott was the director of the Child and Adolescent Service System Program (CASSP) in Kentucky and was one of the key participants in the initial planning for this respite care conference.

Thank you very much Barbara. I guess a carpetbagger is someone who moves from the North to the South and actually I went in the opposite direction so I'm not sure what the correct term is there, but I do have to say that I felt a little guilty when I was involved in the initial planning for this conference and deserted everybody about half way into it. Barbara has reminded me of that a couple of times since. I really didn't find out I was going to be moderator for this panel until about 8:00 last night. Barbara informed me that I would be substituting for Ellen Kagen which is not an easy task. At first, I was a little reluctant to do that, actually, but when I took a look at the agenda and saw the folks who were on the panel I really couldn't resist. We really are privileged to have four such heavy-hitters in the field of respite care and parent support to hear from this morning. It is a wonderful way to kick this conference off. I think it is significant that three of the four panelists that you are going to hear are parents of children with emotional problems; that really sets the appropriate tone for this conference. At least half of the audience are parents and I think those of us who are professionals found out a long time ago, when it comes to the service of respite, parents truly are the experts in this area.

We are going to start our panel discussion this morning by hearing from the lonely professional on the panel. Although Terry Butler currently works for the Multnomah County Social Service Division (Terry's role there is to coordinate case plans and case services for individual children with emotional problems) his claim to fame for being on this panel really stems from the previous job that he had. At that time he worked for Portland State University with Barbara Friesen's staff. Terry was involved in initiating and conducting the first major research study that I am aware of on respite services for families with emotionally disturbed children. Among other things, Terry's study took a look at the professional literature to find out what had been written about respite services for SED children and their families and also tried to identify what kinds of exemplary projects for this population there were around the country. The two end results of Terry's study are contained in your packet and at some point you definitely want to take a look at these. One of them is titled, *Respite Care: A Monograph*, a white document with blue lettering, and the other is a yellow document titled, *Respite Care: An Annotated Bibliography*. These are wonderful resources for people who want to learn more about the service. So I am going to let Terry start by telling us a bit about what he found when he conducted this research on respite care. Terry.

TERRY BUTLER:

Terry Butler is the Coordinator of Multnomah County Connections Program which is part of the Children's Clinical Services program in Portland, Oregon. While pursuing his MSW at the Graduate School of Social Work at Portland State University, Mr. Butler worked for the Research and Training Center on Family Support and Children's Mental Health where he focused on respite care services for families whose children have emotional or behavioral disorders. He is the author of an annotated bibliography and a monograph on respite care services for this population.

Thanks, Bill. People were talking this morning about the first times they heard about respite care. I want to share a story that Barbara reminded me of a couple of days ago. I think it provides some context to what I want to talk about this morning. It was the first time I had heard about respite care. I was involved with a child at a day treatment center and there was really a great community effort put together to keep this child in the community so he could be served there. Agencies got together and put together quite an array of services for this child, one of which was respite care. We were having a meeting in the home and were all ready to set this whole process into motion and some people from the agency said, "You are going to get respite care. One weekend a month somebody is going to come into your home here and you can get away." The caregivers said, "That's nice, but where do we go?" The agency staff said, "Well, we hadn't quite thought of that." The point of that story is that there was one way of providing respite care in that situation and there was one family and the two didn't quite match. The point I would like to make here as I talk this morning is that what we really need to do is look at a system of respite care in the same way we think of a system of care in treatment and in other areas. In your packet there is a very brief outline of some of the models of respite care that I will talk about. I headed it, "Components of a System of Respite Care," and the reason I did that is to raise this idea that we really need a diversity of services, we need a number of ways to provide this service so that as many families as possible can get the benefits of respite care. To back that idea up a little bit, I would like to refer to some themes that recur regularly in the respite care literature. Also they come up a lot in talking to people who provide respite care services and to folks who use respite care services. The themes or characteristics are *diversity*, *flexibility* and *accessibility*. What do these mean in terms of respite care services for families of children with emotional and behavioral problems?

Diversity: There really is no one way to provide respite care services. There are a lot of models that have been developed and that have worked well. Families and children have a range of needs and ideally we have a range of responses to address them. We should work toward developing respite care services that take place in diverse settings and within that there are a lot of different options to providing the services, a lot of different ways that families can receive and use respite care services. It follows that the more options that we have available, then in turn the more families that are going to receive the benefit of respite care.

Taking together *flexibility* and *accessibility*, what that means is that services are going to be adaptable to the multitude of needs that families and children are going to have. It means that issues like transportation, parent work schedules, the level of structure that a child might need, all those kinds of issues are taken into consideration when you think about a system of respite care. It also means that all kinds of children are going to be served, including children and adolescents, that programs are going to be appropriate for both, and that children with the most severe behavior problems aren't going to be excluded from services. One of the things I found when I looked at programs of respite care (primarily they were in developmental disabilities and child welfare) was that children with behavior problems were very, very often excluded from those services. I think we need to make sure that we have things in place to keep that from happening.

With that as the background, I am going to be talking about some of the models of respite care, some of the ways of providing respite care that I have come across. Generally respite care services can be divided into two broad areas -- *respite care services that are provided within the child's home*, the family home where somebody comes in to care for the child, and *those in which the child or adolescent leaves to go somewhere else to be cared for* so that the family can have a break. I'm surely not going to be able to mention every way that services happen within those two areas, but I will try to give you an idea of some of the general types.

We will first be talking about *in-home services*. Basically, this means that somebody comes into the home and cares for the child in his or her own home environment. Within that there can be a number of options. Some of these options for in-home care can be that the provider can be expected to care for the target child only, or the provider can care for the child's sibling, brothers, sisters, cousins, whoever else might be in the home. These don't have to be either/or types of things. These can all occur in combination or as a continuum; they don't have to be mutually exclusive. The provider can be expected to provide only child care or can be expected to be responsible for household chores, meal preparation, or whatever else might be of help to the family -- resembling a homemaker model it is referred to that sometimes in the literature. In the third set of options, the provider can be expected to provide child care only, basic child care, or can be trained and expected to carry out a range of specific activities with the child, tutoring, a whole range of skill development, social skills, for example, perhaps behavior management issues. There have been some research projects in some other fields where this has been done that have documented some of the benefits of respite care. Another set of options is that the provider can be available on a scheduled basis or can be available on a 24-hour on-call basis. The last set, and a very important set of options, is that the respite care agency can train providers and pay providers and then the respite agency is responsible for matching providers and families and having some mechanism to do that. On the other hand, families can have the option of picking somebody within their own network (relatives, friends, somebody in the neighborhood) whom the child might have a relationship with, and then the respite care agency can train and pay that person to then provide care for the child.

There are some advantages to providing respite care in the home. Some of those are that it is easier to have a more specified child/provider match, if there is going to be one provider and one child, there is more of an opportunity to do that. The child can stay in his or her home environment which can be a better fit for the child who might feel more comfortable This might in turn facilitate the child/provider relationship, a more ongoing relationship and the benefits that might come from that. Another benefit is that there is no transportation involved, the family doesn't have to worry about getting the child somewhere, which, particularly if you think about rural areas, might be quite a problem. Overall, this model can be less expensive. You don't have to think about developing a site. A major benefit is that brothers and sisters can be cared for, too. Not only would that give parents more of a break, but it will also allow more options for how parents can use their respite time. That can be very important. Overall, there is just quite a bit of flexibility involved in this model.

There are also some drawbacks to the model. I think I addressed the first one, "Where do parents go?" That issue needs to be taken into consideration. This type of model might involve more difficulty in providing longer-term services not only because of the issue of where parents go but also because a provider is going to have his or her own schedule, too, and may not be available to be in the home for an extended period of time. This type of model involves less monitoring, less back-up and supervision. Because of that it may not work well for all children. Kids who might be expected to have more severe problems might not be appropriate for this type of care. If we think "flexibility" and think of ways to address some of these issues, what about having two providers come in the home or even work in teams? This happens in other kinds of services. I think there are ways to address many of the disadvantages.

Now I will move on to *respite care services that are provided outside the home*, away from the child's home. I have arbitrarily divided those into two general types. These are *out-of-home services in a provider's home*, and the other type would take place in a *structured, site-specific program*, so that there would be *a* place where respite care happened. I'll begin talking about the first type, *care in the provider's home*. This could be an individual's home or it could be a family group home. One option that has been tried in some other fields is to license homes for respite care just as homes are licensed for foster care and other types of care. This would have the benefits of higher expectations for training perhaps; more monitoring might be involved if you are licensed. Another way that has been developed (and I think there are going to be people talking in more detail about this later in the conference) is the *parent coop*, the model where parents exchange care among themselves. That certainly has the great benefits of the parents being in charge of the program, and it has the drawback of added burden to parents, particularly if a number of children need to be cared for at the same time. A way to address that might be to have parents cooperatively manage parts of the program and perhaps be responsible for training, scheduling, and financing and then have other people actually providing the care.

Some of the advantages, looking at the different types of respite in a provider's home, are it can be a personal kind of care; it can promote developing a child-to-the-provider family relationship and family-to-provider relationship. The major thing, I think, is that it provides socialization opportunities, it is an opportunity for the child to be in the neighborhood and in the community. Again, it is inexpensive because there are not a lot of up-front costs for equipment or for the site, and both parents and providers can have a great deal of control in this model. There doesn't always have to be a middle person arranging schedules and all that sort of thing. The drawbacks to the model of care in the provider's home are that it is not always accessible. Individuals are going to have their own schedules and their own time. There may be an acute need for respite care that comes up and the provider might not be available to have the child in their home. So again, the difficulty of providing longer-term services arises. If we talk about licensing, the benefits of training and monitoring might be offset by delays and whatever bureaucratic processes that one has to go through. So the actual beginning of respite care services may take longer than one would hope for.

Now I am going to talk about more formal types of site-specific programs where a child can go to receive respite care. I have divided these into three types. The first is a *group day setting*, which would be for shorter periods only. A second is *residential respite care* which is some type of facility, perhaps a group home, that could provide overnight respite care. The third would be *using existing residential facilities for respite care*. I'll talk a little bit about how these have been used in other areas.

The *group day session* involves a central site (it could be a church basement, school, community center, or other central site) where children can be cared for during the day with trained staff available, with regular scheduled hours. There is a program in Oregon which has an every other Saturday site where parents know that children can be taken during particular hours to be cared for in a group. Access may be on a drop-in basis with a minimum of scheduling, or only available on a scheduled basis.

An alternative to site-specific care, because sites are not always going to be available or there may not be the money to develop a site if that is needed, is some kind of planned, scheduled activity. When Jane Knitzer was in Oregon she talked about a program in New Jersey, I think it was, where kids with emotional and behavioral problems were taken as a group down to the mall every Saturday, they had pizza, went to movies and did things like that. It did provide some time for parents to have some break.

Residential respite care involves a short-term residential facility developed specifically for respite care. The staff are trained in respite care issues, short-term care issues. There are models for this all over the country, if you think about shelter facilities. Most communities have developed shelter facilities. The similarity between respite care and shelter care is its short-term nature. The difference between respite care and shelter care is that access to shelter programs is generally on some sort of a crisis basis. Residential respite care is used on a planned proactive basis, specifically to provide respite care, not as a crisis center. It should be planned and proactive. Part of the program might be reserved in case crisis time is needed, but still the thrust of the program would be more planned and proactive as opposed to a crisis shelter.

The third type of site-specific respite care program is *use of existing residential facilities*. Typically, this is a residential care program in the community. What is involved is the facility reserving a set number of beds specifically for respite that could be accessed by families who meet program criteria. This approach involves more structured care for children and more restrictive care; thus, it may be most appropriate as part of a broader system. It might not be appropriate for some children to be in a restrictive larger residential care facility.

Taken together, these three kinds of programs--the *group day care setting*, a *residential group home* and *using existing residential facilities*--have the advantages of trained staff, more extensive supervision and back-up for medical or other concerns. These programs also involve a certain amount of predictability and they are formal programs. Families will know when and where services will take place. If emergency access is needed, it may be more likely that this type of program, particularly the residential program, is available. Another benefit is that it may involve socialization opportunities for the child or adolescent, a chance to do things with other children.

The disadvantages of site-specific respite programs are substantial and need to be considered. First, all of these programs are expensive. Even the day setting involves some initial cost in identifying the site and buying equipment. Site-specific programs are less accessible than home care because issues like transportation become more significant, especially in rural areas. Limited capacity may also be a problem. What do you do when the programs are full? Problems of clustering children who may have behavior problems also exist. The need for coordination is an issue, particularly with the short-term residential site. But shelter programs have developed many mechanisms for coordinating with the schools and other programs that children might be involved in. These types of programs might be overly restrictive; it may not be appropriate for the child to be in that level of care.

An afterthought to these kinds of formal programs is the idea of having respite care as an "add-on" to other services. Many community programs have kitchen facilities, some have overnight facilities, gyms, pools, etc., that might be used to develop some kind of a respite resource in the community. One is a day program that had some kitchen facilities and some overnight facilities and used those to develop a week-end respite care program for the children served in that agency. It worked quite well, actually. Another idea might be creative use of staff time and perhaps specific funding could be obtained to supplement staff time. There are trained and skilled people out there and some of those folks could be directed toward providing respite care in a variety of ways.

I want to talk about one more general type of respite care service that might be the most feasible in some ways but also is probably going to call for a lot of creativity on the parts of the people who are going to develop these services. That is the *use of everyday community resources*, after-school activities, athletics, camps, art classes, swimming pools, the whole range of things that a lot of people just take for granted and that really indeed provide some break time for parents and a good experience for children. In order for us to use these kinds of activities as respite care, it seems that there are two questions that we should be able to answer. First, how do we assure access for our children and adolescents to community resources? And secondly, having gained access, how do we assure that it is going to be a successful experience for the children, that it is going to benefit them as well? I think the answer to the first question is to work with schools and park departments and others to develop access for all kinds of kids. Part of that process needs to be that we have the resources to answer the second question that, if we gain access, how can we be sure that the experience is going to be a positive and successful one? Some of the ideas for doing that are to have one-on-one time with an adult, have an adult who can spend time preparing the child for the activity and accompany him or her. For example, if the child needs to play baseball on a team, there would be somebody who can spend some time ahead of time playing catch, batting practice--whatever that child needs to be able to participate in the activity, to feel good about it and to have it be a positive experience. Another option is to look within the informal network at friends, relatives, or other people who might have interest for things they do that the child might be interested in and things that the parents might not have the resources to do. For example, somebody may have an aunt and uncle that really like to go fishing and a respite program can provide the equipment for the child or whatever it takes to facilitate this kind of thing happening. Focusing on interests and aptitudes that children might have is a very good first step for helping children move into community activities.

Another point I want to make about using community resources and supporting children is the importance of reinforcing the provider. Whether the provider is an individual or group who is going to help that child be part of the activity, they need to be reinforced in their commitment, in their ability and willingness to follow through and in their consistency. I say that because I think we have all had experience with programs like Big Brother/Big Sister, that are very good programs and they can do wonderful things, but there is often a problem with how long is that person going to be there. What are the mechanisms for making sure that this is going to be an ongoing resource? If we think about developing resources for getting access to community activities, we need to think about what financial or other support is needed to make sure that respite providers are a consistent resource and not just there for a short time.

One final idea for respite care is a respite care fund that may involve a great deal of parent choice. It could be a fund available for parents to develop the respite care resources that they might develop themselves or a program to provide technical assistance, information and referral, and other support and resources families might need to develop their own respite care resources. This might be appropriate for a community in which there are very few kinds of respite care resources. An idea I would like to suggest is that if that kind of resource were available--some mechanism for parents to develop their own respite care resources--I would imagine there would be some very creative ideas that would emerge. These in turn could provide some learning for other families and for people who are developing respite care programs.

That's it for the models. I am very aware that I didn't mention every kind of way that there is to provide respite care. I'm really excited to hear about some of the programs that are going to be presented here. I want to leave with the thought again that perhaps our long-range task really is to develop a system of respite care in the context of family support and with all the great ideas we have here, maybe at next year's conference we will have a whole other list of models to talk about.

BILL SCOTT:

Parents have a unique and personal perspective. They have had varying kinds of experiences with the service of respite. Our presenters are going to tell us a little of what that was like for them. I would like to mention that all three of these women are major movers and shakers in the area of parent support within their own states and also at the national level. Some of you may have seen out on the table some brochures which mention a newly formed parent organization at the national level. It is called the National Federation of Families for Children's Mental Health and I would strongly encourage you to pick up one of those brochures to learn more about the Federation of Families because it is a wonderful effort. These three women who are going to speak now are very much a part of that. The first parent presenter is Barbara Huff. Barbara is from the state of Kansas; she is currently the director of an organization called Keys for Networking, which is located in Topeka, Kansas. She has been very effective in securing respite services for other parents of children with emotional problems but it is ironic that in her own experience when she needed this service the most, it wasn't available for her. I think that Barbara is going to talk about her current efforts to secure services for Kansas parents and also about what her own personal experience was like without this respite care. Please welcome Barbara Huff.

BARBARA HUFF:

Barbara Huff is the Executive Director of Keys for Networking in Topeka, Kansas, a non-profit organization that organizes and provides family support services for families whose children have emotional or behavioral disorders. She is also the current president of the Federation for Children's Mental Health, a newly organized advocacy group for parents of children with these disorders. She is the parent of a daughter who has emotional problems. Barbara Huff is a trainer in the area of parent/professional collaboration and has conducted training sessions in many states and communities across the country.

The editors apologize for the quality of Barbara Huff's presentation; the recording equipment picked up only about half of what was said. Therefore, some information may have been lost, and the dynamic qualities of Barbara's presentation are not evident.

Thanks for this wonderful opportunity, it is wonderful to speak here and be able to have discussions with others around the country. I want to tell you first of all that I direct an organization called Keys For Networking, which is a statewide organization that provides information, support, and training to families whose children have serious emotional disorders.

I want to just describe for a moment for those who don't know me a little bit about my daughter because I think it helps to get a picture of what we are talking about when we describe our children. I have two daughters, one is 22 and the other is 20 and Kristen has been the challenge of my life. She used special education services at age 11. She has been in therapy for a period of over four years, she became suicidal, she was involved with drugs and she had an eating disorder. That gives you a little bit of background. I don't want to spend a lot of time talking about my own daughter.

At this point in time I would like to tell you about how respite care came about in Kansas. In 1987 professionals in areas around Kansas were getting involved in CASSP. Art Sands was the director, and I was involved at that time. Art involved parents in Kansas in the CASSP project. He was involved in the planning of the Families as Allies conference. Art's boss was the director of a community mental health center, and because CASSP was a major turn-around effort in Kansas in terms of family support, she recognized the importance of families. She and I talked one night over a bottle of wine about what respite could be. It was probably at this stage that she said, "Barbara, I've got 24 hours to spend $45,000, to figure out how this can be done. I've got to have a budget." Well, I felt my face falling because it was a real struggle for me to figure out budgets. But we did put in place Rest-a-Bit, which was a training program for respite care providers. The reason she wanted to pay me was what was interesting. She wanted to pay me because she wanted to make sure that the program would involve families. So it was family focused from the very start. Families identified the design of the training. We sponsored six bills, worked side by side with Richard to get these bills into place and present testimony to the legislature in Kansas this year for the provision of services. I would like to say that these families right here at this table are Kansas families with a respite care project provider. You can talk to them for more information.

I want to talk just real quickly about what I have seen respite do for families in Kansas. I've seen what families get when they have this service. It is exciting to watch. When I think about the natural breaks most families have from the day-to-day routine, this is not possible for many families who have children with emotional problems. With a respite program designed for families, these breaks can occur. I can see what happens when the bonding becomes almost unhealthy. Kristen and I didn't have the breaks that we needed. She was constantly with me which was an unhealthy situation. Through our respite program I've watched planned breaks take place. I've also noticed that in many cases agencies don't want your children, the natural breaks do not occur, and parents are afraid they will abuse or neglect their child. So if respite care can help avoid abuse and neglect in some way, it is not a luxury--it is a necessary service. We provide services for the families in Topeka and training for a respite care program. We know it is the bonding that occurs between families and providers that is so important. So it is a private relationship between the two of them--parents and providers--and parents and professionals do respect one another. We need to be able to talk to providers about our kids and be responsible to providers, and providers need to be responsible to families.

It is a sad situation in Kansas that respite care is a traditional service for therapeutic foster parents (and I think that is wonderful), but if they could provide it for foster care families, I can't understand why professionals can't see the importance of this service for natural families. We can't persuade legislators because we don't have an understanding about prevention of placement. They only see this for kids in out-of-home placements. We can say that respite care service is successful because it keeps children from going into out-of-home placement, but we can't provide data about what hasn't happened. We can't say it is effective until it fails to keep a family together. It's real difficult to provide respite and to be able to say to the bureaucracy that we saved you a lot of money by providing this service.

Let me say what I think the pitfalls in Kansas have been and what the challenges have been. First of all my immediate thought when I see a family that does not have stability is that they need respite. I have to constantly remind myself and keep thinking about what this family needs, this family needs crisis respite services and you can't utilize them because they are not available all the time. Costs--respite services in Kansas right now cost a dollar an hour per child up to 20 hours. If a family cannot afford the dollar an hour we use a sliding scale. The problem with this is ownership. The family has to have some ownership. I don't have a problem charging 100 percent as long as it is affordable and the services are effective. Cost is a big factor because agencies think this is just outrageous. If they ever don't have us saying that this is necessary, and you have to do it our way to keep the family together, if it ever gets to the point that we are not around, it may not happen. Flexibility of the agency is another problem. You continually have to talk to them. They tell you, "I don't see flexibility as a problem," and then they turn around and charge and they don't have space, they don't have treatment, and they don't have activities. That's where we are. We have a legislative bill that will be debated soon. I want you to know that in Kansas, respite care has made a difference in families' lives. Thanks

BILL SCOTT:

Thanks very much Barbara. The second parent we are going to hear from this morning is a friend and ex-colleague of mine in Kentucky. Creasa Reed currently serves as a parent consultant for the Kentucky Department of Mental Health and Mental Retardation. My desk was next to Creasa's for a couple of years and I used to listen to her phone conversations and I can tell you that she really raises hell with unresponsive bureaucrats across the Commonwealth. I used to pity the poor professionals who had violated her sense of justice and parent fairness. She really is an outstanding advocate for parents. Creasa is also one of the few people that you might say is in a fairly unique position of having access to plenty of excellent respite services for her own family. I think in that respect Creasa really represents a contrast to most of the parents who are here today and even the other two who are on this panel. So this morning we are going to hear a little bit from Creasa about the respite program that she does have access to and what that service has meant to her and her family.

CREASA REED:

Creasa Reed is a Parent Consultant with the Department of Mental Health in Frankfort, Kentucky. She is a parent of a son with an emotional disorder. Ms. Reed is an officer in the newly formed Federation for Children's Mental Health. She was instrumental in organizing a respite care program for families in Kentucky.

My experience with respite care came out of desperation. My son was kicked out of day care, I couldn't hire people to baby-sit, so I insisted that the public school keep him for six hours and that was my respite. I'm not sure whether I kept him there for educational purposes or because that was my respite. But I was looking at a lot of Richard Donner's material and decided that this was wonderful, it was exactly what we needed. So our respite program sort of grew out of my desperation. I won't talk much about the program, because, first of all, Melissa would kill me and secondly we are going to do that today. My family respite is the pause that refreshes, to use that old cigarette ad. Our respite service is for the family. I think sometimes when we start to develop respite models, we do what they did in a Greek myth. In Greek mythology there was this inn and it had one size bed and when the families come to check in at the inn, if they were too short for the bed they had to get stretched, if they were too long, they got chopped off. Sometimes when I look at our programs I think this is what we do to our families. I think it is important to throw away the usual plan and to start at the beginning to adapt programs to our families rather than to ask our families to adapt to programs. We don't adapt very well. I think it is important that we have unique individualized respite programs for our families. We can talk to any parents in the nation and they will say that they need services to be tailored to their needs. I'm very pleased that this is so important. Well, respite should be just as unique and individualized. Kentucky currently has three respite programs for parents with children with emotional disabilities. They are very similar in some ways but in lots of ways they are different. It is important that they also be culturally appropriate. In the southeastern part of our state, where there is a real high unemployment rate, the parents are not necessarily informed about respite. George Hoffman is the respite coordinator for the program. He had no trouble recruiting providers, in fact he got the cream of the crop. Seven out of ten families that he offered that service to said, "We don't want it, because in Appalachia there is a mind set that says we take care of our own."

I'm very pleased that respite is available. I'm always afraid that I won't get it when there is a full moon or a holiday. If you know our kids, you know that is when we need it the most. I have a lot of choice with my provider. There are two things I trust her to do. I trust her to appreciate my child and not just tolerate him because I appreciate him and I don't just tolerate him. He is a wonderful child, I avoid labels, but he is a very special boy and has a lot to offer any provider. I do try to make it easy for her. I cook her dinner so that when she comes in, I have her dinner ready, I buy her magazines, my son buys her candy and she is really like an extended family member. Since we don't have a grandma around for 120 miles, she is filling that role nicely. We are starting to appreciate her bonding now. More importantly, on Saturday, my son starts to say, "When is Wanda coming?" I don't mind, I'm not at all jealous. This is my time with my hubby to talk and I like to talk with my hubby.

I guess to show you how my family lived a little bit before we got respite, we were in the kitchen one day and it was a very stressful time, and we had absolutely no respite; we were waiting actually for our project to begin. My son was going to run away from home and my husband was giving him all the logical reasons why he shouldn't. I was standing there and I was cooking and I was thinking, "I don't know what they are saying, I don't care, it is not important, it doesn't concern me, I want them totally out of my life, I'm not here." All of a sudden this muscle in my chest just went squeeze and my husband said he heard me gasp and at that point I just felt myself shaking and he took my arm and sat me down. He asked what was wrong and he said I think you need to go to the hospital. So we got to the hospital and they took my pulse and immediately started putting machines on me and took me back into this room. My pulse was about 72, then 104, it went crazy. The doctor says, "Would you like your family back here with you?" I said, "Are you trying to give me a heart attack? Keep them away from me please, don't let them back here, keep them out there, please." So they kept me on monitors, they decided they had better give me an EKG because I wasn't getting better. I was lying there thinking I was going to die, and I thought that wouldn't be so bad. I really don't have a fear of dying, I have really strong religious convictions, and I think I've dealt with worse things in my life already. So I was lying there, they finally gave me an EKG, and the doctor said, "I want you to know Mrs. Reed that the bottom chambers of your heart have no disease and that's very fortunate because with the stress you are experiencing, you could have had a real heart attack because you don't have a healthy heart." I said, "I know that already, I live like that." Anyway, he said to me, he kept me back there an awfully long time, he said, "What is causing your stress?" I started to tell him and he walked back in there and said, "Is your son the one with red hair?" I thought, oh, he is noticing my beautiful child, he is very attractive, you know. And then when I finally did get ready to go home, the doctor kept saying, "What can I do for you?" I said, "You can't do anything for me." I walked out to the waiting room and I looked down and my son had systematically removed every page from all the magazines in the waiting room. So I knew how the doctor figured out that he was my child. It wasn't necessarily that he was so attractive, but that he had destroyed the waiting room. I guess that if you look at respite as being necessary, you know, my experience with the doctor was a little bit of respite, but it isn't one to model.

Anyway, my family is really fortunate to have services. We do have respite, we do have additional respite funding and I know that other families are not so fortunate. I get angry and I get mad and I get disgusted and I cry when people have to put their kids in hospitals because they don't have any respite. I get really angry about that. I don't think that should ever have to happen. Fortunately, I don't think that is going to happen in my family. I keep thinking that it can't get any worse, but it does. When a year or so ago I was out of my home for four months and I was saying to my child, this is it, this kid is the very worst, it will never get any worse than this. I was wrong. It got worse and we did some other things. Respite has kept my son with us, he is growing, he is more socially acceptable. He says weird things, and he will always say weird things, but he is more socially appropriate, his head is up now, his back is straight. It is really important, you know, to look at all the strengths. It is sort of like going to IEP meetings, you have to look at all the strengths. Respite has helped my family to deal with the everyday trauma, and we have not put our son in a hospital and I'm telling you there was a time when he needed to be there. I didn't believe the doctors who told me that but they were right. We stuck that out and I don't think we could have got through that period if we didn't have respite.

I wish all parents were as fortunate as we are. I know there are those who don't have what we have. We have worked really hard to get where we are with respite, and I would be glad to share our model with anyone. Just remember, when you look at families, it takes an extraordinary parent to parent these children. You know what it is like to parent your children, imagine ten thousand times worse. We just got a new diagnosis, obsessive compulsive disorder, we got that one on Friday and we knew that anyway, this kid can go on and on. Just imagine if your teenager wants to learn how to drive and you multiply that by a thousand and you've got my child. I think that is exciting that more people know about respite. Two years ago I didn't know what respite was until Barbara Thomas gave me a survey and said, "Fill this out." I was about three quarters down the page until I realized what she was talking about. "Thank God, this is exactly what we need," and I went to my parent group and said, "What do you think about this?" They said, "Oh, yes," and the kids said, "Oh, yes," because they like this as much as we do. I think at the conference here we have an exciting opportunity to view a lot of different models and models from different states that we are fortunate to have here. Thank you.

BILL SCOTT:

Thanks very much, Creasa. Batting cleanup for our panel this morning (it's World Series time so I thought I would try to use some baseball analogy) we are privileged to have a parent from the state of Vermont with us. Her name is Judy Sturtevant. Like Creasa, Judy is a parent consultant with the Vermont Department of Mental Health, and she is also a member of a state-level CASSP committee in Vermont. Unfortunately, despite Judy's knowledge of a system of care in the state of Vermont and despite all the contacts she has with professionals both at the state and local levels, like so many other parents, Judy has been unable to access respite care for her own family. Some of what Judy is going to talk about this morning is what that has been like to not have respite care available for the family.

JUDY STURTEVANT:

Judy Sturtevant is a Parent/Consultant with the Department of Mental Health in Vermont. She is the parent of a son with an emotional disorder. Ms. Sturtevant was instrumental in the development of a family support program for families of children with emotional and behavioral disorders in the State of Vermont.

Thank you, it is a pleasure to be here today. When I found out I was going to present, they said, "You are going to be on a panel," so I looked at this table and all that. They said, "There are going to be microphones." I don't know if I can do this. I walked in and I saw microphones on the table, and I thought, "Well, that's OK." Then I found out I would have to stand *up* and do this. And I am standing, but this is it. It is a pleasure to be here in Kentucky. This is my first trip to Kentucky and I hope it is not my last. It is nice to hear that you are thinking about other years for this conference, and I hope I can come back and contribute. I'd like to find out how many parents are here who have had or could benefit from respite care for their emotionally or mentally or behaviorally troubled child? I hear respite talked about as a break for parents but I really go beyond that definition. I look at respite as sometimes preventing a relationship between, as they say, two consenting adults from dissolving. That's a reality for the parents that live with these type of children every day. My hat goes off to the single parent families, it really does. I have the utmost admiration for those parents who struggle with this day in and day out by themselves. I don't think I could do it. Fortunately, I have a very capable husband. We have been married for 18 years and I know I look like I could have a 20 year old. But I am fortunate that I have that type of relationship. I know a lot of people that don't. Sometimes I wonder when I am in my worst, my lowest spot, I think, how do they do it? When do they come up? Where do they get that extra strength to go on? I call up my husband at work and say, "You have to come home, because if you don't come home, I'm not responsible, I'm not responsible for what happens." Fortunately, he has been at his job for a number of years so he has the flexibility to come and go and he will come home and I will literally walk out the door. But what do those single parents do that don't have that flexibility? It just blows my mind. To those of you out there--you have my utmost admiration.

Respite also means to me the prevention of a child from leaving his or her home to go into an unnatural environment. As Creasa alluded to, too often that is the case, that children go into hospitals, residential treatment centers, foster care, simply because there hasn't been any planned break, for no other reason, but just for respite. It is very easy for those institutions and those foster parents to get respite, but it is not easy for natural parents to get that. That is a sad situation.

I'm going to talk a little about Vermont's Respite Care Demonstration Project, not too much because I'm giving a workshop this afternoon, and I hope some of you are coming. I brought a map of Vermont so you will know where we are and where we fit into the bigger scope of things. Vermont's Respite Demonstration Project models Richard Donner's Kansas project and I am proud to say that. I think that it is an exceptional model, and I am glad Vermont chose to adopt that model. I'm very proud of it. My role on that project is to provide technical assistance to the statewide mental health centers to continue that project. I enjoy that very much. One of the eligibility criteria for our project is that the families cannot have access to respite monies from other sources. Vermont is, from what I understand, unique in that we have a children's Medicaid waiver and the waiver allows for some families to have a funding source for respite. Those families that have a child on the waiver program are not eligible for this program. Those children who are in SRS custody, because SRS in Vermont has a funding mechanism for respite care, are not eligible for this project. This is strictly for families who have nothing, absolutely nothing, and in a sense that is how it should be, when you are starving. I feel you have to give everybody a shot at it. But how that translates for me is, in my personal situation, is my son is on the waiver, so we have a monthly access to a pot of money for respite, but I don't have respite.

Let me tell you a little bit about my son. I have two children. My daughter is 14 and in raging adolescence, and for those of you have adolescent daughters, you know where I am coming from. Sometimes I think that she is emotionally disturbed, too. My son will soon be 13, so they are only 14 months apart chronologically, but emotionally, they are miles apart. He was diagnosed at the age of 2 1/2 as being hyperactive with attention deficit disorder, which tells you what, other than I didn't get a whole lot of sleep. His behaviors have manifested themselves so that he does have a diagnosis of severe emotional disturbance. In January, he developed a new behavior which is agoraphobia. This started out in school and has just manifested itself in that he absolutely refuses to leave the home, and is in fear of his life. So, what that means for us is that we have to restrain him to get him to school. We do that because he needs to go to school. I never thought of the educational process as respite, but it sure is for me at this point in time. We get him nowhere else. Other than school, he is home. He has threatened to commit suicide if we try and take him anywhere so we don't. The last 2 1/2 years he has had five 10-day emergency placements in a residential facility as well as a year and a half residential placement. So our picture right now, unfortunately, is not one of progress but more one of regress.

I didn't know what respite was either, and as I was sitting here I was thinking, "When did it dawn on me what respite was?" I guess when it dawned on me was when he outgrew, and I don't mean agewise, but he outgrew the definition of having a baby-sitter and his behaviors did not allow him to have just a baby-sitter anymore. When I think of some of the things that he has done to baby-sitters, I don't know why we haven't been hauled into court or sued and had to put our house up for sale. It is just amazing the number of baby-sitters I have gone through but also what he has put them through.

So I have access to respite money but I do not have anyone to provide respite in the summer. No names are available. I am in the process of trying to find capable people to take care of him. He has blown out of family day care situations, and I've had to leave my jobs several times because there is no one to take care of him. I thought I had found a good caretaker for him. There is a woman in the community who did day care in her home, and she is very highly regarded in the community to this day. Her house is immaculate, she does activities with the children, all those wonderful things you look for when you are looking for someone to take care of your child. Then the fateful day came that she physically abused him because he brought her to her limit. I know how he could do that because he does it to me all the time, but it was one of a parent's worst nightmares when your child is emotionally disturbed, to have a child physically abused by his or her caretaker. He was abused with a belt, he had black and blue welts all over his back, from the middle of his back to behind his midcalves. It was because he ran away from her and she just lost it. As I alluded to earlier, I have had to give up several jobs that I have had over the years because no one wants to take care of him. It has also forced a relationship between my husband and myself to be independent from each other, separate from each other, so it is hard when we get back together again at the end of the day, if we are not exhausted, to relate to each other about what is going on for us, personally. I hope that I will be able to come back here next year with a more positive story for you. I know from experience in Vermont that families that are receiving direct respite care service through our project are receiving wonderful care, and they have wonderful stories to tell. You will hear some of those this afternoon. I hope that next year maybe I will be one of those parents, too. Thank you.

October 29, 1989

P.M.

BARBARA FRIESEN:

I think it was about four years ago when I got a call from our federal project officer in Washington, D.C., who said, "Barbara, there is this fellow in Kansas you ought to talk to." And she said, "His name is Richard Donner and he is doing something or other out there and I'm not sure what it is, but he is doing some kind of parent study or something." So after that phone call, Richard and I first met by telephone and actually on the phone, I think, discovered that we were close to kindred souls and then we have gotten to know each other very well over the last four years. It is my pleasure today to introduce our luncheon speaker. Richard is a lot of things. Richard has the role of training coordinator at Washburn University in Kansas. He is also in private practice and does consultation on case management and respite care. He is also working at the University of Kansas School of Social Welfare on a very important study called the Family Caregiver Survey which is one of the first studies about what families who have children with emotional, mental, or behavioral disorders need, or want, or think or do. This survey will gather some more information that will help us all be able to speak more clearly about the needs of families.

Richard will play a very important role in this research project. I see that his role on the project is to remind the other academic researchers to remember the families--that they need to be involved, we need to ask them about the research, and we need to be sure we are not drifting too far away from the purpose of our work.

Richard's job today is to tie together how respite care connects with other parts of the service system and the system of care and he is very well qualified to do that. It is my pleasure to introduce to you Richard Donner.

RICHARD DONNER:

Richard Donner is a social worker and a Licensed Clinical Specialist in the State of Kansas. He is also an assistant professor at Washburn University in Topeka. Mr. Donner is currently a doctoral student in the Social Work program at the University of Kansas. Mr. Donner has extensive experience with children and adolescents both in direct service and administration over the last 17 years. His research interests are in the area of family self-help, advocacy and support groups.

Thank you Barbara. It is really humbling for me to be here and also very exciting. When my name gets mentioned up here on the podium throughout the day, I begin to think, "Oh my God, what do these people think about me." I hope I can only begin to demonstrate a little bit of what people seem to have the faith in me, in some of the things I have just had really a unique opportunity to be involved in and do.

I have to tell you about a person, myself, who started out five years ago, after being an administrator, a trainer, and a clinician for about 15 or 16 years, of thinking that I really had my act together and that I was a pretty good folk when it came to helping people. I was trained in social work, I was beginning to work on my doctorate, I was going to train other people to do what I thought we needed to do to help people no matter what their issues were. I had an opportunity in Kansas to begin to be involved with our CASSP project. At that point, five years ago, I didn't know what that even meant, but I was soon to find out that we had a whole lot of things we needed to understand differently and that I certainly as a professional needed to understand differently.

I had a plan at that time to ask parents what it was they felt their children needed. I thought that was a pretty logical way to deal with the issues we faced and the problems that we knew were there. I found out it wasn't just logical, it was also pretty novel. It was also considered by many of my colleagues as being extremely radical. You don't ask people who are "dysfunctional or crazy or sick or have caused their kids problems" what they need because we know what they need. They don't know what they need. We are definitely going to be the ones to tell them how it fits and what to do. Well, I had a unique opportunity in Topeka and then in six other communities in the state of Kansas. It was a lot of hard work going through some professional organizations and agencies to even get them to try to access families, which is a whole other story. I met with some parents, that was about a dozen parents in Topeka about four and a half years ago, and asked them to tell me what it was like and asked them to tell me what they needed for their child, for their son or daughter to be able to stay at home, or even the services that they might want. They went into a two and a half hour discussion with me. It was them talking to me and they let me know in no uncertain terms I needed to shut up and take notes. I was a doctoral student at the time, and I still am, by the way. Anyway, I think it is important to note that not so much what the families said, because many of you have heard that and many of you have heard it this morning, but rather what it did for me as a professional, a person who really prided himself in his capacity to deal with people and be up front and to be real responsive and thought he was pretty flexible. I found out I hadn't even begun to meet the needs of families. What I thought was important--in doing family therapy or helping them through a therapy process of making changes in their life--wasn't what they needed or wanted at all. But that's what we had done, and what I had done personally, was not something I really could be very proud of after that date. So as a result of that I've taken the position that many of us in this room have and that I think we as parents and professionals alike have got to really move forward with now, is that the bulk of the people out there still believe what I used to believe and we have a long hard road ahead of us if we are really going to get the kinds of services that we know are so necessary and essential for families to keep their child in their own home, in their own community, in their own school, and with their own friends. But that didn't happen easily, it didn't happen easily for me, and I don't think it will happen easily outside.

But I think it is a challenge to all of us as we look specifically at the service of respite care. That may be one of the cornerstones or one of the places we can poke people, we can jar people in a way that may be useful to all of us in the long run. My agenda is much bigger than respite care. My agenda is one that I really believe that the only way we are going to be able to provide the services for families and children is to do that in the most comprehensive way possible, the most individual, flexible, diverse way possible. Of all the words and stories you heard this morning, I would only underscore them and also tell you that what we need to do that is to do that with every service that needs to be in line for families if we truly believe that families and children ought to be together.

Some of the things that I've learned in the past four years I want to share with you in terms of the changes that I have seen us begin to go through in this country. I travel a great deal so I am able to see people and go a lot of different places. I have been in many parts of this country consulting on various issues of child mental health. One of the things I see beginning is a shift from *institutional care* to *community-based services.* A few years ago that wasn't even considered. Community-based services was just a nice idea, some ideal that people talked about. We know that for many other populations the deinstitutionalization movement in the last 20 years has been a dismal failure because those services weren't there, whether it was for the adult chronically mentally ill or for the mentally retarded children or for other service populations that are in need of services. We have begun to see the move away from institutional care. We have begun to see a move away from a narrow view of treatment. When we entitled this presentation "Enhancing Treatment" I really had to begin to think about what we really talk about when we say treatment. How does it really fit with what we talked about and what I was taught when I was an undergraduate or in graduate school? I was really trained to believe that treatment had to be done in an office or treatment had to be done in a traditional kind of way of one hour a week of family therapy or whatever that might look like. I think what we have to do as we begin to hear families and we begin to respond to them is to broaden our view. That's really exciting when that begins to happen.

We have to shift, I think, from a pathology focus to a strengths focus. It seems to me that for too long what we have looked at is what caused problems--what is a problem--rather than what people have as capacities. People in some other disability fields are much further ahead in this arena than we are, and I think we can borrow from them and use their knowledge and skills to begin to look at people's capacities and functioning and abilities rather than what is wrong with them and what doesn't work. When we do the latter, where we only look at the pathology or problems, what we end up doing is thinking that nobody else can tell them what needs to be done than those of us who are the professionals on the other side of the table.

We have also seen a shift from separation of children from families as being the answer to a position of being that families need to stay together which is something that we always knew and something we always said, but we never really put into place and into action when it came down to the kinds of behaviors and policies and programs that were being designed for families, no matter what the kinds of issues are that they hold, what or what kinds of issues are that they face. We are beginning to see this more and more as the country begins to look at costs and other kinds of issues and I think at the total quality of life.

What we know is that we have a lot of problems out there, and those problems are related to poor funding, are related to fragmented and uncoordinated services. Those of you who are familiar with Jane Knitzer's study in 1982 called *Unclaimed Children* know that she documents that better than any other. A new study that she has recently completed on the education and mental health systems and their lack of really working collaboratively together, I think will just continue to support the fact that we have a long way to go if we are begin to really provide the kind of services necessary for children and families. Family services for the most part have been designed not to keep families together; they have not been family centered. We ask the question many times, "Can we provide the services for this family," rather than the question, "What is required for this family to be able to keep this child in their home and their community?" If you ask it in the second way, all of a sudden there isn't a "no" answer, there isn't a, "Gee, we don't have the service for them." It becomes the responsibility of all of us to begin to design the services so that the family can maintain the child in their own homes and communities. Another thing that we know in terms of the problems that we face in the mental health system and the other systems that serve families and children is that most of those services are outside of the home. And we don't even provide people with secondary supports like transportation to get there and then we label them as being resistive and uncooperative and in ways that are not useful to them at all and definitely don't enhance our building any kind of rapport and relationships.

Another problem with services is that they are only available after there is serious damage done rather than to prevent that serious damage from being done. I happen to be one of the people who believe that parents don't wake up in the morning and think, "How can I screw up my kid." I think that parents, every one, whether they have a child with special needs or not, definitely understands the stresses of being a parent. I think we have to begin to learn about that and understand that in the context of what is normal for everybody else. Stress for families is not any different for families of children with serious emotional problems than it is for other families, it just gets exacerbated, it gets worse, and you have heard about that this morning. Stress results from an imbalance, an imbalance between expectations and what is real. Stress results from an imbalance between demand and resources. Stress also results from an imbalance between what a person gives and what a person gets. For families that have special needs children, the day-to-day stresses are enormous, and this has been supported in the literature about caregivers of all different types whether they are caregivers of elderly, caregivers of developmentally disabled, caregivers of chronically ill, all experience emotional stress, financial stress and a narrowing social perspective. As you have heard this morning and as the families here can attest to, the isolation is probably one of the most serious as it relates to this disability.

What do we need to do? It seems to me what we need to do is to understand what we have already learned in some other populations and I am going to draw on some of the literature that is out there on the DD population because they have done some really good work as respite care specifically has begun to address some of the needs and the stresses of families. One of the things that the DD literature supports and shows us is that *there is a reduction in family isolation, there is an enhancement of family functioning*, and most importantly, *there is a maintenance of the child in the home as an integral member correlated specifically with respite care*. So, what are the resources that it takes to provide the balance for the demands that the family faces in trying to maintain their child in the home? I think they were manyfold, but let me mention a few. First of all, *it takes good physical health and stamina*. As I talk about these I want you to think about them in the context of family support, because that is really what we are talking about. What would it take to be able to support families in a way that gives them a way that they need to be able to keep the child in their home. They need good physical health and stamina. These people have a lot of stamina but not always good physical health. *They need good mental health and emotional health and support for that.* They need information and support to be able to gain that kind of mental stability that isn't very easy when you are so stressed and you feel that you are about ready to burst. *They need emotionally strong relationships and healthy interactions. They don't need to be blamed and put down.* What they need to be is to be told that they are doing the best they can and let's figure out what else we can do to help them gain the kinds of support that they need. *They need those relationships with the people that they care about the most.* You heard this morning, just in a microcosm, the incidence of divorce or marital dissolution because of the fact that the stress gets so great for the families that they can't take it any more. That, we know, is supported with data across disabilities, and I would profess that it is so to an even greater extent with this disability.

Families need time, which is where I think respite fits in more than anything else. *Families also need money* to be able to provide the necessary kinds of supports for themselves and for their children. *They need* more often than not--which is real unfortunate because of the fragmented and uncoordinated systems that we have--*skill in negotiating the service system* as it is today. Probably the literature supports this more than any other: *they need a support network of other families and friends.* For every parent that's here, I would hope that you would connect and network with every other parent that's here and get to know them and when you go back home, find a network that is available to you and if you don't have one, get one started, because that for you is probably going to be the most beneficial thing that you can do and will give you a kind of respite that you will never get any other way. Parents also need information, they need a whole lot of information about what is this disability, how do things go, and how do they progress, what kinds of ideas can they have in terms of what is going to happen next, what kinds of things work for certain kinds of behaviors. They need professionals that support all the things that I have mentioned above, not just a narrow view of looking at services as being only institutional, residential, foster care, individual therapy or family therapy. What we have to do is begin to provide the range of services from one end of the continuum to the other rather than only having the services that are so prevalent in our society which are institutional and one hour a week of therapy kinds of care that is available to families for the most part. There are many families, according to the studies, that don't even have that available to them.

Respite is part of the solution, but not the solution. Barbara cautioned you about that this morning and I want to caution you about that also. It is critical, it is an essential service, but it cannot be viewed as the only service. If you stop with this, we will have lost, we may have won the battle, but we will lose the war. I am very concerned that when I train providers that they don't find themselves in a position of having to provide all the other kinds of services that are so desperately needed by families just because the other service systems are not in place. So be careful with that as you go out and begin to build respite systems or a system of respite care in your community or in your state. Respite care does reduce stress, respite care does allow for the child to stay at home, it improves family functioning, and it prevents family deterioration and it reduces inappropriate placement. We have to have a full continuum of services and only then will we begin, I think, to provide the kind of necessary supports for families. If the premise that most children with emotional disabilities remain and live with their family at least until adulthood is accepted, then I think we must begin to see family support services as basic services, and I even would go further than that and say they have a right to those services, rather than just seeing those services as ancillary and only necessary when damage is done rather than preventing it. I think only then can treatment be truly enhanced.

As a clinician I no longer behave in the way that I used to. I don't interact the same and I don't provide services in the same way. I am much more responsive to what families ask for and what they need because they know better than I could ever know. I really firmly believe that 95 percent of the professional community out there does not buy this notion. I guarantee you that if you think that there are a lot of folks around that do, you are right, but they are all right here in this room and maybe a couple of others. So I think it is our job to educate and it is our job to advocate. That's the only way it is going to happen. It is going to happen through everybody joining together in making sure that respite care, which I think is a fantastic focus for bringing about the kinds of changes in the system of care and beginning to build a continuum of service, I think it is a perfect opportunity to place our votes and our pressure and all of our energy behind it, but remember that it is only the first step and remember that you have got to continue to move towards other kinds of services as well or I guarantee you that respite care will fail as it has, or as other services have, if other things aren't in place. I think we have to change our view, I think we have to change our attitudes about families, I think we have to understand them from their perspective, and when we do that, all of a sudden there are possibilities that are endless and ones that I never dreamed were possible are more possible than ever before. Just like this conference is. Thank you.

BARBARA FRIESEN:

We have just a few minutes and one of the things we wanted to encourage was any interaction. Are there any questions for Richard, anybody wants to make a comment about what he had to say? I encourage you to do that. Yes.

Question: Please tell us more about the family caregiver survey.

RICHARD DONNER:

At this point we are just at the very, very beginning of it. We are at the point of hoping by the first of the year that we are going to be selecting one state that we are going to go into and study extensively as a comparative study. So once that selection is made, we are looking at doing the research itself next summer. I would anticipate that the report and the data will be out probably about a year from then. So it will be the next couple of years. That doesn't mean that we won't have lots of information that we can start sharing as it goes.

Barbara just reminded me that the Portland Research and Training Center already has information from the National Parent Survey; that information is available. The summary is available now.

Question: What are some ways to improve the relationship between parents and professionals?

Some of the best ways that I have found is that when you bring parents and professionals together for another purpose than a treatment focus. I will use the Families as Allies as the best example of that which came out of Barbara's ideas and then Portland Research and Training Center is an evolution of that process, what it does is it brings parents and professionals together in a way that says, "Hey, you know we really have to find a way to work together." And that education of parents and professionals understanding each other's position and understanding what it is like, the stresses that there are for parents, the stresses that there are for professionals, all of a sudden those barriers begin to get broken down. We have seen incredibly wonderful attitude shifts on both sides within a few day conference. I happen to have been involved in about four of the regional ones and a number of state and local conferences. Every time I was just amazed at how, in a very short period of time, people can change what they think about professionals as well as parents. I think it is a two-sided stream. That's one of the best options I know out there. Probably there are many others.

Question: How can we get more information about the advantages of community-based treatment?

I think that the best information that relates to this disability is the National Mental Health Association's Invisible Children's report. That does a really good job of delineating the costs of institutional care versus group care versus community-based care. I think it is that kind of data that come from those resources that you have to have or else it isn't considered reliable and reputable. Are there others that you know?

BARBARA FRIESEN:

The picture actually is not all that clear. I guess I would caution all of us against selling community-based services as necessarily being that much cheaper than residential services or foster care. It depends. One of the ways that often community-based services are cheaper is that you don't provide all the same things in the community that you provide in residential care. So we have some studies, but there nothing that is that definitive, partly because of what Barbara was talking about this morning. If you have prevented out-of-home placement, you always have the problem of proving that it would have happened if you hadn't done what you did. As Barbara said, if you move children out of something very dramatic, like out-of-state

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placements, for example, you can see the thousands of dollars that are saved. But if you don't have children in out-of-home placement, if you have them in their homes, you can only speculate as to how many might have gone in the other direction. So, yes, there are some, on the whole residential care is more expensive, but I think we should be very very careful about not selling it too hard that way. That mistake has been made with other disability groups and then state legislatures are very unhappy when in fact, it is not cheaper, and the quality of care may even be lower.

Question: Can you give us some ideas about how to influence the legislators in our state to improve services for children and families?

RICHARD DONNER:

Yes. I think it is important though just to remember that legislators are more prone to listen to numbers and money, unfortunately, than quality of life issues. And yet, as Barbara mentioned to you this morning, six families went and had a major impact on the legislative interim committee in Kansas, and I guarantee that they didn't talk costs, they talked about what it is like. That moves people in ways that I certainly can't ever move them because I am not a parent. I am just a professional.

Specifically on respite, but it encompasses other family support, doesn't it Terry?

I think it varies depending on what your state initiatives are. I think respite is a nice place to start if there hasn't been that kind of connection with the people that make those decisions. Respite is usually one that people can get on the bandwagon for very quickly because we already know the outcome. We know that for the developmental disabilities population, for example, that it really does help, it makes a significant difference. I think it has to be a coordinated effort in lots of different directions coming at all the various services. I think one of the things we have to do is to get parents information. Even here this morning many parents never even knew the word respite and what it meant. We talk about intensive case management services and people don't even know what that means, or crisis intervention services, or family preservation services, so part of it is just an education process to start with. Then you begin to work and advocate for all those services. There are plenty of models out there now through work being done in Florida and Georgetown, and Portland, and some of the other CASSP initiatives. They have really clearly lined up the kinds of components that should be in a system of care. If you are not familiar with the components of a system of care, I would access that information so that you can put together the plans that are necessary and then you begin to work through that process. In Vermont, for example, they have a system of care with about 64 services. If you want that list I would just suggest that you get in touch with Judy [Sturtevant], or somebody there in Vermont, and tell them you want to see what they have put together in terms of what the idea is. They have worked out a whole plan for the next five years and how they are going to implement those services. As you heard, it isn't implemented in the way it needs to be, Judy can't even get some of them, but at least that is a way to go about doing it. There is a law, P.L. 99-660, a planning law, that says that every state must have to plan for mental health services, every state has to have a plan for children. So one of the places you might want to start is to find out who is doing the P.L. 99-660 plan and what are they saying about kids. In our state we had to make all sorts of noise, they didn't even include them. So those are a couple of options. So thank you all, have a good afternoon.

BARBARA FRIESEN:

This afternoon, between 3:30 and 5:00 you will have a chance to meet with other people in your state to begin thinking about planning for respite services. I just want to remind you that the task is to look at the need you have in your state, the resources, and to formulate some goals. Then tomorrow morning, work on strategies about how to get there. We are going to hear a report from all of you tomorrow afternoon at lunch. So at 3:30 today you will have a chance to begin moving in the direction that you need to move.

October 30, 1989

A.M.

BARBARA FRIESEN:

I'm very pleased to introduce to you the moderator for this morning's panel. Ellen Kagan is Director of Technical Assistance at the Georgetown University Child Development Center, CASSP Technical Assistance Center. Ellen is going to talk a little bit more about what CASSP is. We talked a little about that yesterday. Ellen was actually the very first and only person in the Technical Assistance Center when the CASSP program began in 1984 and she had spent, before that time, a year lobbying on Capitol Hill for Congress to pass the CASSP program. So she is very intimately connected to that. At that time she worked for an organization called the National Association of State Mental Health Program Directors, fondly known as NASMHPD, and specifically for an organization called the State Mental Health Representatives for Children and Youth, better known as SMHRCY. I think it was a wise move to move from working in "SMHRCY" at "NASMHPD" over to something that is as clean and crisp as "CASSP". Ellen has a long-standing interest and experience in the field of mental health and her interest in children, she says, especially grew while she worked for the National Association of State Mental Health Program Directors and with the State Representatives for Children and Youth. Ellen has not been able to be here for the entire program. She has a new baby and her offices are moving today so the fact that she is here is really a minor miracle. We are very pleased to have her. Ellen was a part of the planning group that met in Kansas City and thought about and talked about planning this conference a couple of years ago. We are very, very pleased that she is here and she will moderate this morning's program.

ELLEN KAGAN:

Ellen Kagan is currently the Director of Technical Assistance at the Georgetown University Child Development Center, Child and Adolescent Service System Program Technical Assistance Center. Previous to her work with CASSP, she worked for the National Association of State Mental Health Program Directors and their program for State Mental Health Representatives for Children and Youth. During this time she functioned as a lobbyist in Washington, D.C. on behalf of families and children's mental health.

Thank you, it is really good to be here. I know we only have an hour and a half, and I know that these panelists have so much to say. It is also good to see a lot of faces that I recognize. I have been on maternity leave for quite awhile and have not had an opportunity to see you, so hello to everyone. Barbara asked that I give you a brief overview of the program that has been called CASSP. As Barbara said, I have been involved with it for so long. It is truly the only thing that Congress has funded specifically for children's mental health. It was also one of the only new programs funded in the area of human services during the early Reagan years, which was a minor miracle. How many of you are from CASSP states? I am so glad because actually there are only three states that don't have CASSP grants so unless you are from Michigan, Minnesota or either Wyoming or North Dakota (I'm not quite sure), you should have raised your hands because CASSP has now grown into almost a nationwide program. We started in 1984 with 1.5 million dollars. At that time, the states were really ready to get involved with something. Children's services in states were in disarray, there was a book out called *Unclaimed Children* which basically was an indictment of the entire child mental health system. It particularly targeted state mental health agencies as failing to meet their responsibilities for these kids. So from that grew this movement and 34 states applied that very first year which is unprecedented in federally funded programs. Unfortunately only 8 were funded. Now, as I mentioned, 47 states plus the District of Columbia and the Virgin Islands have CASSP grants. So what is this thing called CASSP?

Unfortunately I can't give you an organization that I can actually put my finger on--I must move you to this sort of philosophy program called CASSP. CASSP is a philosophy basically. It basically says that children should be in community-based programs, there should be family involvement, and all of the principles that we have been talking about with regard to respite care, are all part of the foundation of CASSP. The program part of it is a grant to states, $150,000 maximum, so we are not talking about a lot of money, for states to begin activities that will build this system of community-based services. The first goal of CASSP was to make sure that in every single state there was at least one person, one name, one phone number that people could call to find out about children's services. So it was providing that leadership capacity. At the time there were some folks already in state government who were very interested in children's services, but many, many states didn't even have one person. It might have been 1/5 of a person's time, it might have been a chief psychologist in the Department of Mental Health. I can say that in that area we really have been very successful.

The second thing we wanted to look at was developing this range of services. As most of you probably know, there are two kinds of services out there for kids. There is an hour of therapy a week, outpatient services, or very intensive hospitalization or residential care. There was very, very little in between. So the movement of CASSP says, "Wait a second, kids need more than just these two kinds of components. Let's see what we can do to develop this continuum."

Kids who have emotional problems don't only need services from the mental health department. As you know, they need services, and I'm not telling you anything new, you could be telling me this, kids need services from a wide, wide range of agencies. So the third basic premise of CASSP was to say, "Hey, we want you folks in mental health to get out of your offices, to go talk to people in child welfare, talk to people in education, talk to people in juvenile justice, in health departments, in mental retardation departments, and begin to coordinate yourselves and talking to each other." I will tell you this, in many states, in most states, this was a revolutionary idea for mental health to do this.

Another area of the continuum of care that needed to be among the basic principles of CASSP was the issue of family and family involvement and family support. To that extent the CASSP grant encourages all CASSP project directors to work with families. How many of you were involved with the Families as Allies projects that were funded several years ago? Actually that is kind of neat to see so many more people on board.

The Portland Research and Training Center was funded by the National Institute of Mental Health and the National Institute on Disability and Rehabilitation Research to provide a lot of the support for family involvement or family networking.

Another area that rose to the top was the involvement of minority persons and the mandate that services be culturally and ethnically sensitive. A vast majority of the children in mental health services are from culturally different backgrounds than the majority and services need to be relevant to them.

Finally, after the states have gone out and done all these things, then we need to take a look and evaluate, and see if we are we doing what we should be doing, is this the direction we should be going. I can tell you, I am very close to the program, and maybe I am not quite as objective as some people outside, I think with the small amount of money CASSP has been given over the years, they have been able to leverage a tremendous amount of people. In many states it has literally become the base of a movement to broaden and expand children's mental health services. So I encourage you, if you do not know who your CASSP project director is, contact them to say, "Hey, I am Mary Smith and I'm from Hoboken and I want to help," and I'll tell you your CASSP project director will put you to work. How many CASSP project directors or CASSP people are in this room? Maybe you can actually stand up because I would like to see your faces. I am glad we have such a good representation.

Now CASSP has been involved in respite in a way since March of 1987. We did a survey, this was in the infancy and some states weren't really sure that parents were even out there and the question was, to CASSP project directors, what is it that your parents need most? If you could pick one thing, this is just what you think, that you think parents want most, what would that be? We collected the surveys, and overwhelmingly the answer came back, respite care services. At the time, we didn't know a lot about respite care. We may not know a lot about respite care services even to this day. Portland has done an extraordinary job in collecting and disseminating and networking states around respite care and through a project's director's meeting in March 1987, we explored the issue with each other. So CASSP has been involved.

I also bring greetings from the National Institute of Mental Health that funds the CASSP project and funds the Technical Assistance Center at Georgetown. They are very, very pleased to see this conference take place and hope that they can become partners with all of you.

Now to move on to the panel. The topic of this session is the National Perspective. I would first like to introduce Ted Boyden, to my right, who is an evaluator with the General Accounting Office. GAO is the investigative and auditing arm of Congress. GAO only does what Congress asks it to do. About a year ago, two subcommittees in Congress, the Select Committee on Children, Youth and Families and the Subcommittee on Special Education, contacted the GAO and asked them to do a national survey on respite care services in general. And luckily they found Ted Boyden in the Detroit office to be their chief evaluator and head honcho of this project. Ted is what we call in this business a lifer, when you ask Ted how long he has been with GAO he says, "26 years." When you say, "What did you do before that?", he will say, "I was in college." That 26 years has spanned a tremendous array of topics and ideas. Ted is also what they call a generalist, he has worked in areas like energy conservation, welfare, education, insurance, military procurement. This is the first study that Ted has done with children, although he has done work in the health area. The tone of

The tone of Ted's report is intended to be neutral and objective, and it is not part of his job to be an advocate. Ted, I am so pleased that you are here. I would like to introduce Ted Boyden.

TED BOYDEN:

Ted Boyden is currently an evaluator for the United States General Accounting Office, in their Detroit, Michigan office. The General Accounting Office evaluates programs at the direction of Congress; Mr. Boyden has been involved in a number of evaluations over the years. His current work is focusing on respite care programs across disability groups around the United States.

Thank you, Ellen. It is an honor to be here today. Before I talk about our study, I would like to introduce one of the two persons who is working with me and has been very helpful in analyzing the data and gathering information, Annette Graziani.

Last November 1, 1988, almost a year ago, we started the survey of respite care. In March 1987, the committee on Special Education asked us to testify. So our study has been broken into two parts. For the first part, we gathered information on national associations and federal activities involved in respite care. What we found in both cases was that the activities have been very limited. There hasn't been a lot of federal money in respite care and what there has been has been very recent, really since the middle 1980s. Most of the money, in fact, has been in the last couple of years. I don't know if you are all aware of it or not, but in 1988 and again in 1989 there have been a series of demonstration grants awarded by the U.S. Department of Health and Human Services (HHS) for respite care and crisis nursery projects. They have been extended for two more years. On October 25, 1989, Congress authorized the extension of the program for 20 million dollars in 1990 and 20 million dollars in 1991, as a maximum. There is no assurance that 20 million dollars will be available. In February or March of next year (1990), appropriation hearings will be held and an amount will be set. After that, Requests for Proposals (RFP's) will go out from HHS to the states requesting them to apply for grants for either new projects or continuation of existing projects. So keep in mind, if you have any questions about that, contact HHS and they can give you information.

The second part of our program involved the study of two aspects. The first aspect was a questionnaire to 25 states. This was quite involved. First of all it took us two months, two people, just trying to identify what state officials in 25 states were involved with respite care. There was no central focal point in the state. We would call one person, they would refer us. In some cases we had to call about 25 people just to identify 5 people in the state that had programs that were providing respite care services. After we did that, we sent about 125 questionnaires out to officials in these 25 states. We got 111 responses back which I think is pretty good. That is almost a 93 percent response rate which indicates that the people we sent them to are interested in respite care. They wanted to give us the information they could about their programs.

What I would like to do is to talk a little bit about the preliminary results of this state questionnaire. When we went out, we asked a series of questions and one of the questions was, we asked them to identify what children, what disabilities were eligible, what families were eligible for respite care? They had various classifications: developmentally disabled, retarded, emotionally disturbed, physically handicapped, mentally handicapped, and so on. What we found was a little bit to my surprise because I was here in January talking with Ellen and some people in the Cincinnati area, that 31 of the programs, about 28 percent of the programs, had families of children with serious emotional disturbances and this was in 23 of the 25 states we surveyed. I may add, off the record, that this was a surprise. It was my impression earlier that there were not that many respite care programs out there for parents or caretakers of children with serious emotional disorders. Another thing we found, and again this really wasn't a surprise, that over 90 percent of the programs, or a little more than 9 out of every 10 programs, respite care was one of many services offered by the program. It was not the only service offered by the program. This was important. Later on when we met in focus groups with parents, with state officials and providers, it was pointed out that respite care, to be effective, must be part of an overall group of support services, that it cannot be by itself. Our report will reflect that. We will reflect the views of those officials and it will also reflect statistics from our state questionnaire that respite care by itself cannot be effective.

I've done a separate analysis of these 31 programs. I would like to do a little bit of comparison between the programs where severely emotionally disturbed children were eligible to the total, 11, just to give you some idea of how some of these questions came out very similar and how some of them were a little different. Most of the programs start eligibility at birth and discontinue at age 18 and 21, so most of these programs were for children or teenagers--I guess you can still call them children--and they were not for adults. This may be because of the information we asked, we told them we wanted to focus on programs for children. Respite care is also offered and is available to older Americans, but the Congressional committees specifically were concerned about respite care for children and that's how we directed our survey. We also found that few programs, and I mean very few programs, had income ceilings where parents would be eligible to receive respite care services. This is important because if it does limit the parents, they must use their own resources or find other ways of getting respite care. What we did find, and this is where we have a little difference, is about 40 percent of the total programs did require the parents to pay part of the cost of the program on a sliding scale. In contrast almost half of the 31 programs, 15 of 31 programs, involving children with serious emotional disorders, did require the parents to participate financially. So that ratio is a little higher for those programs. Why, I don't know, we didn't get into those details. We also found that almost 40 percent of all programs had waiting lists. We asked for information about these waiting lists. Unfortunately, the information we got was very limited. Only about 8 of the programs of the 43 programs that had waiting lists, gave us information about waiting lists as far as numbers or families on the waiting list. It does indicate that there is a demand out there from the state aspect, from the state program aspect, that is not being met. This demand would include children with emotional disorders.

We also found, I don't know what to make of this, but we found the programs where children with emotional disorders are eligible, had a higher percent of other disabilities eligible. What I mean by that is, when we look at the total programs, about 30 percent of the programs have children with emotional disorders, yet these programs have about 50 percent also that are mentally retarded as compared to about 40 percent of all programs. What I've seen is that the programs where you have children with emotional disturbances as an eligibility category also have many, many more other disabilities eligible. What you are seeing is that they are including other categories. Children with emotional disturbances aren't the only eligible categories in these programs. To what extent these programs are providing services to children with emotional disorders, I can't say. Only one-third of the programs out there were able to give us information on the numbers of families. But they reported about 45,000 families were receiving respite care. What does this mean? Just what it says, about 45,000 families. It doesn't mean that there are another 100 to 200 or 20,000 families out there are receiving care for which they did not provide us information. But when you look at that, it is a very small percentage of the families out there that would be eligible for respite care. I did a little information gathering that identified well over a million school age children that fall into three categories and these three categories are categories I consider as being at risk of abuse, neglect, or institutionalization, and they are mentally retarded, emotionally disturbed, and multiply handicapped. There are about 1.1 million children out there being reported by the Department of Education as having a disability. The states that we went to, and even though we went to 25 states, it was the larger states, they had about 80 percent of the children, only reported about 45,000 people being served. There is a gap there. How much I don't know. The committees would like to have us tell them how much that is, but not in one year. In order to do this it would require an extensive amount of more work than what we can do in the time period we have. But there is a gap out there some place.

The next thing that I want to bring up briefly is that since we have started this work, we initially contacted the Texas Network and we were trying to find out what was out there, and in doing so we have been trying to pull together a directory. A directory is only good at the time you put it together. But what I found out is that most states don't have a directory, most states are not able to tell you what is out there as far as providers or programs that are out there. This is a gap which I feel from a family standpoint, from a parent's standpoint, is very critical. The families who need respite care need to have some place to contact. They have to have somebody in the state or somebody in a large city to call. Now in some cases, there are county mental health departments, social agencies and others that they can refer to. I have found the Texas Directory to be very useful and I have found a couple of other state directories to be useful. I have been called and have been able to give people referrals from these directories. Hopefully, before we finish our audit, and I'm not going to promise it, we hope to pull together a directory and have it available, and we are going to try to encourage some federal agency to take on this responsibility of updating and maintaining this directory. So state officials, providers, and families can have at least some contacts in the states if they want to get information about who has the programs, where the providers are and just some information about respite care. That's really the highlights of the program. What we hope to do is sometime next spring, in an April or May time period, is to issue a report to Congress. The report will summarize the information that we have obtained from the states and also focus groups.

About the focus groups, one of the things which we found out talking to focus groups does reinforce to a great extent what Richard talked about yesterday. We went out to talk to state providers, state officials, and some providers in Boston last July at the Family Support Conference. In the Detroit area we talked to families that were receiving respite care and families that were not receiving respite care. And a lot of what Richard was talking about yesterday has been reinforced from this contact. What I would like to do now is basically go over a few of the things from these discussions. We found out that for children with emotional disorders and children who are technology dependent, on respirators and other machines, there is a scarcity of trained providers. There is a real problem in getting people to serve as providers for these groups. We also found that for older children, teenagers, there is a problem in finding providers. Siblings leave the home, grandparents can no longer take care of them, and that there is a gap out there. We also found, and probably to nobody's surprise, that states are limited in the funds they have. In some cases the legislatures have a cap, in some cases they just run out, and because of that there hasn't been an extensive effort to publicize the programs. Some officials told us, "Hey, we don't publicize the program because we know we can't meet the demand if the word gets can you do about that? Well, as parents and as providers, if you feel you need these things just put the pressure on, contact people, and find out what you can do to relieve this gap. Now in budget crunching time, this may be a problem. We found this to be true. We also found, and again this reinforces what Richard talked about, is that families have told us what happens when they don't get respite care or get adequate respite care: families break up, siblings have problems coping, children are institutionalized, bad things happen. It was also pointed out, and I may have mentioned this before, but I will now, is that a lot of officials and providers felt that there needs to be a state focal point, there needs to be somebody in the state that people can refer to. This is not only brought out by state officials but also brought out by providers.

One of the questions they asked us to do as part of this survey, was to find out what the federal role should be. That's a bombshell. What we found out from talking to officials, parents and providers is, they feel that whatever federal role should be is that federal funds should supplement and not supplant existing funds. They feel that if the federal government is going to move from funding demonstration projects to a more permanent funding in the order of child support or something like this, these funds should supplement and not supplant what funds are being used by state and local agencies out there. They also told us that they felt that the states should have a commitment and that the states should have a matching amount to the federal monies, that it should not only be federal but it also should also be a state commitment. How much? I don't know, whether it should be one to four or one to three or one to two, I'm not really capable or ready even to say. But they felt the states should have a commitment.

Finally, as I mentioned before, everybody said, without a doubt, it was a consensus with all five groups, that respite care has to be a part of an overall package of services, it cannot be by itself. I can't emphasize this more and it will be emphasized on our report. Thank you very much.

ELLEN KAGAN:

Thank you Ted. As I said, sometimes when you listen to national speakers you get kind of a national perspective. When Ted starting in speaking, he said that 23 states had eligibility criteria for seriously emotionally disturbed, I thought, "Wow, that's incredible, I think that's terrific." Then Ted said quietly, "Well we don't know actually how many kids are actually utilizing these services." So we still have a long way to go.

The next person I would like to introduce is Milton Cassady from the Texas Respite Resource Network. The Texas Network has been in existence for only four years which I was very surprised to hear because to me they are sort of synonymous with the word respite. When you hear the word respite, who do you go to? You go to the Texas folk. They have only been around for four years. They were funded by the Texas Planning Council for Developmental Disabilities. They were originally funded to provide networking in Texas alone and found that just wasn't enough. The networking has now extended to the entire country. They do a lot of public education, they believe that networking is one of the best ways to reach out and to work with different people. We have two representatives here. As I mentioned the first one who is going to speak is Milt Cassady. He has been with Texas Respite for two years. Prior to that he worked for 13 years with an MR/MH center in Austin, Texas. When I asked him why respite was so important to him, he thought about it for a second, and his colleague Liz pipes up and says, "Because he has a heart as big as Texas." But really, Milt has actually been a pioneer in this area because he started the very first Texas respite program. With that I would like to introduce Milt Cassady.

MILTON CASSADY:

Milton Cassady is the Information and Referral Specialist with the Texas Respite Resource Network in San Antonio, Texas. Prior to this, he worked in a Mental Health/Mental Retardation center in Austin, Texas. The Texas Respite Resource Network is a non-profit organization working with respite care programs and issues covering all disability groups, mainly in Texas but recently expanding nationwide.

Thank you Ellen. It's very exciting for Liz and me to be here from San Antonio and representing Texas Respite. We have got to meet and put some faces with some names of individuals that we have been speaking with over the last couple of years. With some of you out there, we have had some very long conversations on the phone. So it has been a great opportunity for us to finally put some faces with some names and to meet you personally.

Liz and I are going to address some national trends we have seen develop in the area of respite care. In terms of kind of the history of respite care, I'm not going to go into that in any detail. Terry Butler, in his monograph which you will find in your packet, did a very good job of kind of outlining where respite has come. It did start out with the population of mental retardation and the developmentally disabled and since then has really grown. One of the exciting things that we see at Texas Respite has been the conceptual application of respite care to other groups of individuals with disabilities. As I said, it started out with the MR and DD population. The frail elderly and individuals with Alzheimers are now doing some very exciting work in the area of respite care. The National Association for Alzheimer's Disease and Related Disorders within the last year has developed pilot projects all around the country helping adult children who are now taking care of their elderly parents in their home. The group for the persons with serious emotional disorders are now very interested in respite care. From a personal perspective, I think one reason why we have seen it grow--and why respite care kind of keeps moving on to different populations of people--is that as people fall through the cracks of our service system, it doesn't take those groups long to come up in arms and start demanding services. I think that is, from my own perspective, what has happened with the population of children with serious emotional disorders. They did not qualify for mental retardation services, they did not qualify for developmentally disabled services, and parents really did not have anything. We see that the advocates and the parents now have created a unified voice, they want services, they want services that are tailored to their children and to meet their family's needs. So while we have come a long way, I think we still have a long way to go in that regard.

With regard to other groups that are using respite now in Texas the Multiple Sclerosis chapter has just within the last year started a very exciting program covering close to 90 counties in Texas providing in-home respite care to families who are caring for a member at home with multiple sclerosis. Just from the contacts that we have in Texas and round the country, the groups that I think are going to be next in line are the victims of strokes, because a lot of those individuals are going home and families are caring for those individuals who need 24-hour care, and also the head injury and spinal cord injury individuals. Right now those individuals also do not qualify for mental retardation services, they don't qualify for DD services, particularly if the injury occurred after the age of 22, which takes them out of the federal definition of developmental disabilities. I think we are going to continue to see respite care apply to different populations of people. The trend in our society is that we are advancing with technology, keeping infants alive now that would not have survived delivery 10 years ago, and we are keeping the population of our elderly citizens alive a lot longer and we have to do something with regard to family supports for these populations also.

I started running a respite care program in Texas back in 1977, as a result of what we were hearing parents tell us that they needed. In 1980 I attended a respite care conference in Cleveland, Ohio. Up until that point I thought I was the only person in the world doing this thing called "respite care," that no one even knew how to pronounce the word. I will never forget the feeling when I walked into the opening session and I saw 200 people in this room in Cleveland, Ohio, and I thought, "There are 200 other crazy people trying to that do this." Respite care didn't fit with what my agency did, it didn't fit under typical mental retardation services, it wasn't vocational rehabilitation, it wasn't case management. We were trying to make life easier for these families. That didn't fit any of the definitions at the time. So I always kind of felt that I was the red-headed stepson within my agency. I did that for seven years. The keynote speakers at that conference were Rutger Warren and Shirley Cullen, who I would consider to be the movers of respite care and got it going back in the mid-70's. I really see respite care as the pioneer in the development of what we now call family support services. As Ted has said and what Richard said in his luncheon address yesterday, respite care cannot stand alone for families, families need more than respite care, respite care is an integral part of the array of family support services that we need to offer families and we need to provide to our families regardless of the population we are serving. I think that respite has that distinction that it did lead to the broader genre of what we are now calling family support services. Respite care is an important part of that.

With regard to what we have seen with respite care services developing for the population of children with serious emotional disorders--I think it is because parents got tired of falling through the cracks and being told that they weren't eligible for these services, that they did not meet the eligibility criteria. And now we have reached a point were services are being targeted specifically for this population. We really kind of see a two-pronged approach going on in the area of developing respite care services for the population of children with serious emotional disorders. One is the activities that we see going through the CASSP projects where programs are developing, that are developing specifically for this population. The second approach is that programs that historically served the mentally retarded and developmentally disabled populations are trying to broaden their eligibility criteria to include children with emotional disorders.

It remains to be seen how effective programs are that have traditionally served the MR/DD population and are now also trying to serve the children with emotional disorders. I think that there are two fundamental differences with regard to respite care services for this population as opposed to what we have traditionally provided for the MR/DD population. The first of those differences is the *training of the providers*. At this conference I think you have had some excellent opportunities through Richard Donner's presentation and what he has done with the Rest-A-Bit curriculum to really look at competency-based training curricula that are specifically designed for this population. We are looking at a skill level of provider that is different from the level of providers that have traditionally served the MR and DD population. I think this is going to be one major difference in the program design of respite care programs, the skill level of the providers that the programs will need.

Secondly, there seems to be a shift with regard to one of the primary purposes of respite care for the SED population. Those of us who are respite care purists at heart have always touted that respite care is a family support service, the primary purpose of respite care is relief for the primary caregiver. We at Texas Respite still believe that very strongly. What we do see occurring, though, is that the programs serving the population of seriously emotionally disturbed children are incorporating a second function of the program which we have not traditionally done, and that is that the respite care itself may be more therapeutic or treatment oriented in nature than what has been traditional in respite care programs in the past. In some programs it appears that the actual respite care may be an adjunct to the child's treatment regime. Obviously, with these children the respite care provider is going to have to be very familiar with what is currently going on with that child with regard to, for example, behavior management. The respite care provider needs to be consistent with what the family is currently doing with that child and what the primary treatment team has determined is going to be the most effective way to manage that child and for life to be a little bit more pleasant in the home situation.

We really see those two areas as primary differences that we see developing in the area of respite care for this population -- the training of providers and that the focus is also now incorporating a somewhat more therapeutic or treatment orientation in nature. Some programs are actually using their respite providers as role models for the parents, for example, to role model for parents on how they might more effectively deal with destructive behavior. That is a little bit different from what we have done traditionally in the area of respite care. We have been more concerned with just having warm, loving, nurturing providers taking care of these children while their parents were able to get away. With this population I think it is going to require quite a bit more on the part of the provider to do this effectively so the family is going to feel comfortable in leaving.

Another trend that we have seen with regard to respite care is in the area of training and really the shift moving toward a competency-based training curriculum. In the past with the MR and DD population we have primarily been concerned with first aid, CPR, a general orientation toward developmental disabilities, an orientation of seizures and anti-convulsant medications, that type of thing. What Richard Donner has developed with the Rest-a-Bit curriculum is real exciting. Phyllis Tarrant in Oklahoma has developed some excellent training curricula also that are also competency based and John Parrish and Nancy Neff have also developed an excellent curriculum for the MR and DD population that is competency based so that youth providers have to exhibit that they have obtained and met the training objectives for each one of the levels of the training package.

In Texas we work not only with the MR and DD populations, we will work with anyone with regard to respite care program development. We feel that many of the program development components for respite care are the same across the board. We can work with you on tailoring specifically what you need for your population. So feel free to call us. Liz and I sometimes get cauliflower ears from the amount of time we spend on the phone. If you have problems with your budget, call us and we can hang up and we will call you back because we have lots of money for long distance calls. Thank you very much.

ELLEN KAGAN:

I hope you will all avail yourselves of those services. As Milton was talking about this thing called "Re-SPITE" that he wasn't really sure about, it reminded me of a story I told you in 1987. In March we did this survey of CASSP project directors and respite came up as being the number one thing that they wanted to talk about. When we got to the conference there was one, I will not mention his name and I will not mention the state, he came up to me and said, "What is this thing, this Rest-pit ?" and in his mind he had visualized this big pit where you put all the parents who wanted to get rest. We have come a long ways since then. The next person I would like to introduce is Liz Newhouse, who has been with the Texas Respite Network for 2 1/2 years. She is also the parent of a child who has mental retardation and epilepsy and has been involved many, many years in the development of community-based services in her hometown of San Antonio. While her children were in high school, which I guess is also another form of respite, she went back to school and got her MA in theological studies. And the things that are most important to Liz, as I'm sure you will see during her discussion, are family unity and family survival and systems change to make the system work for a family. Liz Newhouse.

LIZ NEWHOUSE:

Elizabeth Newhouse is the Assistant Director of the Texas Respite Resource Network in San Antonio, Texas. She is a parent of a son who has epilepsy and mental retardation. Ms. Newhouse is a strong advocate for families and has been involved in the development of community-based services in the State of Texas.

Thank you very much. I think, as Milton said, it is a real privilege to be asked to come here and learn from the experts about the situations that families are living with. The more that people learn from one another, the more we have a chance to change systems. I always come wearing two hats. I'm a parent and a professional. Before I put on my professional hat, I want say a few things as a mom. I am an advocate for families. I think that the status of families in America right now is in deep trouble. We all know this. We watch families fall apart, we have systems set up so that in order to get help, they almost have to fall apart. We have families call us from all over the country and we have to say to them sometimes, "If you get divorced, you can get services. If you declare bankruptcy and go on welfare, you will get services for your child. If you give up custody of your child, you can get services." That is not right. We need to have statistics, we need to have good programs, but we have to have them based on values. America has always been very strong on values, and I think we have to get back to that. That is where families come into play.

It has been encouraging at this conference to see so many families. Will all the parents here raise your hands? I want to talk to you for just a minute. I don't know if it is your experience, but what happens to me when I come to a conference, is that I get excited. It can be a real mountaintop experience, to hear all of these good things that are going to happen, to hear all the philosophy, and to get all jazzed up. But then you sort of crash. Has anybody ever experienced that? You get all excited and see all these people doing things in other states, and then you go home. From the mountaintop it is a long way down. When I first starting going to conferences, I wondered why I would go from just being exhilarated to just in the pits of depression. I thought, "What is wrong with me? It is exciting what is happening." We hear the philosophy and boy am I an advocate for all these things and I believe them on a philosophical level. I also have to live in the real world, I have to live with the level of services that are provided for my family and in my community right now, today.

It is a hard thing to balance out. I know that there have been a couple of parents that have come up to me in discussions yesterday, and said, "How do you do all this, it takes so much time and I am out doing all of this and yet my family still needs me?" I think that is something all of us have to resolve. It is the families that are going to make the difference to help change the system but you always have to balance out, how to cope with your own situation at home. It is a difficult decision for families.

Another concern is that many of us who have children with different disabilities do not know much about one another. We think that our own situation is always so unique. We all have stresses. Anyone who is dealing with a child with a disability lives under a tremendous amount of stress. I believe very much in independence, productivity, and integration of individuals with disabilities. I believe in the people-first language in which we don't talk about "emotionally disturbed" children but we speak about "children who have emotional problems", or we have "children who have mental retardation." They are not "retarded." We name the person first and then the disability. It is an important thing to start talking like that, it is a habit we can learn. We hear "handicapped children" all the time. No, they are children, there are a lot of things that can describe that child, one of which is a handicap. This is a more positive way to talk about any of our children. My son has epilepsy, he is not an epileptic. He is a person, he is a six foot tall 17 year old who has a lot of problems, but he is not just one thing. All of us need to think about labels and how we talk about our children.

I will share a situation we recently experienced with our son. We have chosen to put him in a private school, not in our city or in our state, in order to get some services that he cannot get in Texas. So for me, as a parent, I am talking about family unity, and I can't get that in my state. I want more for my child than is happening right now and it has been a difficult decision. This summer he was home for about four or five days for his birthday, and we went to the grocery store. As I was telling Milton, it is always exciting to go to the grocery store, and of course, I can't leave him at home. I thought we had done really well, we had pushed the cart around several aisles, we had only bumped into about four or five people but we hadn't knocked anybody down yet. We got over near the dairy case and Scott started to have a seizure. I managed to wedge myself between the cart and have him lean over me. He is 6 feet tall, but we didn't fall down, and at the end of it, in the post-seizure period, he looked just fine, but he was jamming into everything, and we were in this dairy case trying not to spill everything. Meanwhile everyone was trying to ignore us or trying to figure us out. So, I too, have had some crazy experiences that are similar to some of yours, even though my child has mental retardation and epilepsy.

The important thing is when you crash when you go home and look at the lack of services, to know that what you have gained at this conference is that you are not alone, that you have been heard, that deep down in your gut you know that it isn't right that your children can't get those services that they should be getting, and it gives a reason to fight. You can even find a sympathetic professional once in awhile, like a Richard Donner, or even more amazing, a sympathetic bureaucrat like Bill Underwood, you know, they do exist. You can pick up the phone and you can call when you feel discouraged and you can have a network out there to help you get through the tough times. There is no one way to survive. The key to survival is to network and talk with one another. It also is important through these conferences to keep a list of people to contact. In our state people call Texas Respite Resource Network because we are not tied into state funds so we can be a gadfly. We can call up state agency people, and we have even threatened to blow up Austin several times. I think it is often easier to just start all over, since our systems have not progressed to where the families really need them to be. Bill Underwood and I were talking about this yesterday. There is a Protection and Advocacy agency in each of your states, and it is a wonderful source for advocacy for your needs. We use Advocacy, Inc., which is our protection and advocacy agency in Texas, all the time. They are also independent of state monies, set up to be advocates for you and your child. Use groups like this when you are fighting the system.

Now as I put on my professional hat, I would like to comment on something that Milton also spoke about: Family-Centered Care. Many agencies and advocates are using this concept and respite care is one of the services which give support to families. As respite care is becoming more sophisticated, as more funding becomes available from various sources, that funding will have with it certain restrictions or requirements. Respite care is moving away from the mom and pop organizations. The increased funding is both a blessing and somewhat of a curse. Established funding brings with it stability; programs are able to plan ahead. On the other hand, monies from various sources also can mean more regulations and bureaucracy. Thus there is a tight rope for programs to negotiate. How to assure quality, stable programs for families that do not become bogged down in red tape which can threaten flexibility and responsiveness to meet the families' needs.

In respite care the client is the family. The end product of the service is respite and this happens only if the family feels they have received a break from their caregiving responsibilities. That is why in the generic sense, schools are not respite programs. There the main purpose is to educate the child. One of the by-products for families when that child is in school can be respite because the child is out of the home. The distinction is important because when we ask for specific funding for respite care, we have to watch out what we are asking for. Legislators and funding sources are very particular. When we ask for money for respite care, we have to be sure that the prime purpose is relief for the primary caregiver. For example, it is important for children to get away and to experience a camping situation. A by-product of the camp is respite for the parents. So we get respite from a lot of things but when we are specifically talking about starting respite programs, we have to be very careful in how we do that. Funding is going to become a significant issue.

Another thing is the issue of liability. Someone mentioned that, "I don't want to talk about that, it's not a lot of fun". I'm sorry to report that as programs are being developed, liability issues must be dealt with. Across the country, there has been recognition by various states that some sort of regulation for respite care programs is necessary for quality assurance. Several states have addressed the issues of liability including Maine where providers are trained and can obtain insurance. The state of Massachusetts has written respite standards and Florida is currently in the process right now of writing respite care standards for children who are medically fragile. It is critical as standards or regulations are written for respite care programs to maintain the concept of the family as the client. Our goal is to provide respite care as part of the natural process of parental caregiving. Parents want that care to be responsive and to meet their high standards of care, but there is a real danger in over-regulation.

One of the areas of concern is the administration of medications. Depending on your state medical practice act or nurse practice act, as the case may be, a problem might exist. The regulations often state only licensed professionals can administer medications. If only a nurse can administer a medication, then that would exclude a trained respite provider. We all know it is not necessary to have nurses perform these tasks in most cases. In respite care the provider acts in place of the family -- as a surrogate parent. It is called in legal terms "in loco parentis." If that right is taken away from us as families, if only a nurse can administer medications, if the standards are that strict, we are all going to be in trouble. Respite care across the country is going to be in trouble. It isn't enough to ignore it. We sort of ignored it in Texas, we didn't want this happening in our state. But the MHMR system came out with new standards this year and in the respite care standards it states that only a nurse can administer medication. Now that is scary. We are now behind the ball, we are trying to get it changed. Do you know how hard that is? Texas is under a federal mandate and in a knee-jerk reaction their attorneys said, "Oh, we can't do that." We talked to people in the state mental retardation agency, and they said, "We wrote these standards for adults." I thought they were being funny, but they weren't. I said, "What about the children?" They said, "There are children involved? What are you talking about." I said, "What about the child you can never self-medicate? Have you ever thought of that?" They said, "Well, no." I said, "Then these standards will not help families." So this is a problem. If programs are over-regulated, with restrictions like this, families are not going to use the care. It is truly up to the families to fight this.

Another aspect of liability issues: I have worked with a group in Texas called the Human Services Risk Management Association. This is a non-profit agency which offers training on proactive risk management systems for human services programs. It is important that as respite care programs are developed that the directors design pro-active policies and procedures. It is no longer an option to be a good person and do a good job. It isn't good enough any more just to say, "I am helping someone and therefore I am immune to being sued." Did you know that in Boston, this last August, there was a meeting of the American Trial Lawyers? Do you know that among other things on their agenda, they discussed how to sue non-profits? They start the process by trying to find a violation of a government regulation -- federal or state. Because of the large number of complex regulations that already exist, once some infraction can be cited, they can successfully proceed. All respite care programs must guard against incomplete policies and procedures. Be proactive. You can't afford to be negligent in this area. On the other hand, don't let the threat of liability issues stop the development of services. We need to work together to assure quality without over-regulation. If this issue is a problem in your state, call TRRN and together we can network with others who are dealing with these issues.

Finally, there is an issue of how we protect our families from providers who have not received proper training. According to a quote from the Human Services Risk Management, "Is it really to the public good to our most vulnerable citizens, our children or elderly or poor, to be served by individuals with only a few hours of training or by inexperienced or underpaid staff?"

So as service providers we must have quality, well-trained providers, but again, we don't want to be over-regulated. This is a dilemma. If your agency is concerned with these issues I urge you to contact the Human Services Risk Management Association. I have made copies of some of their materials. They are available to work with state programs and to do training on liability issues. If you are interested in some of things that they have been doing, you might want to take a copy. If you have questions about them, talk with me. Thank you.

ELLEN KAGAN:

Thank you very much. I would also to thank all the panelists for making my job very easy because we now have 20 minutes for questions or dialogue with the panelists or dialogue among yourselves about some of the issues that have been raised this morning. I want to open the floor for questions.

ELLEN: Are there any questions. Yes?

Question: I'm Cheryl Kinkaid, I'm from West Virginia and I am a parent and a professional and my question is for the gentleman on the end here. I understand that in some states there are parent advisory committees for the respite care programs. Are there plans for a national parent advisory committee, to serve as a feedback to your organization?

TB: I don't know.

EK: Do you think that's a good idea?

CK: Only parents know what parents need. Like Richard brought up yesterday, the professionals are go-betweens. The parents are the ones you need to go to for information.

MC: Texas Respite will be hosting a second national conference either November of 1990 or March of 1991 depending on the hotel availability of San Antonio. During that conference we will have a special parent track that is going to be just for parents to express what their needs are and then the parents from that track will bring those issues to the professionals. Other than that we are not aware of any national movement currently going on that might address from a national perspective what the needs are.

EK: I think that one of the things I learned from my experience tromping through the halls of Capitol Hill is that it is very important for national organizations to collect data. Because lawmakers do need the big picture. But it is equally important for them to hear your individual stories. I am telling you all when I first walked into a Congressman's office, my knees were shaking, I was scared to death. I thought what on earth would this person want to listen to me for. They want to listen to you. I am telling you something, you don't even have to talk to the representatives themselves, because if you can talk to their aide, and get them to understand, really understand what your individual situation is, that person can become your advocate and work on your behalf. So I would encourage all of you, yes, a national parent advisory group is one good vehicle, but that does not release you from your individual responsibility of making your story, your own personal story that you know better than any organization is going to know, and get that to your representatives.

Question: Hi, I'm Creasa Reed from Kentucky, and I have two things to say. In Kentucky we have a state task group for respite issues comprised of both parents and professionals and we also did a needs assessment survey in 1987, to assess needs for respite with Kentucky parents who have children with emotional disabilities. Also, on the national level, the Federation of Families for Children's Mental Health is a strong advocacy group, it is a parent run organization and believe me, we are going to be watching out for respite and looking out for policies and federal regulations that govern respite . . . so we hope to have a national voice.

TB: I would also suggest that you try and contact a couple of the subcommittees in Congress. The one subcommittee that is very active and is very proactive in this area is the Select Committee on Children, Youth, and Families. They are one of the groups that asked us to do the study. They are very interested in respite care. The person you may want to contact on that staff is Jill Kagan.

I kind of know them as the demonstration grants for respite care and crisis nurseries. Is that what you are looking for or do you want more information?

EK: Maybe I should give you sort of another Washington perspective. It is really a miracle that those monies came into being. It is not a lot of money, but it came into being during a time when there hadn't been a lot of new federal programs being initiated. Again, it just hones in the point that the more families speak, the more that they will be able to work with the agencies that provide funding for the much needed services to come about.

Question: My name is Jerry Frampton and I am from Austin, Texas. One of my concerns is the kind of arbitrary cut-off dates, the kind of arbitrary decisions that are written into legislation that for many of these children, when they reach 18 or 21, there is no change, they are not going anywhere, there isn't any use to that rule. Could we address this on a national level to eliminate some of those arbitrary cut-off dates?

LN: Often what happens with appropriations and legislation is that they have to have restrictions on them and limits by virtue of trying not to fund or to solve everybody's problems, so by the very nature of what the bill is or what the problem is that is trying to be solved, some sort of limits have to be set. We fight, I know in Texas, we have a different eligibility criteria for every group, for every state agency, different territory, the state is carved out by every agency differently, so you don't know if you are in a mental health region, or a retardation region, or a human services region, or an educational region. The boundaries all shift and change. It is totally confusing. The more families can fight on a local state level to change these things, the more it is going to be heard. This summer we had a series of focus groups and public hearings throughout the state of Texas, as every state has had this year, through the Developmental Disabilities Planning Council processes, to report on the status of services to individuals with disabilities. That is one of the biggest things that came out in Texas was the huge mess of eligibility criteria and how families can't walk through this morass of different eligibility criteria and different boundaries. It is not easy. All I can say is that there are important things to be done on the federal level, lobby for them and voice your concerns about being left out and falling through the cracks, but also do it on the local level.

EK: I think for programs to get off the ground, they need to stick to eligibility criteria. Even for the Children's Justice Act, as I understand it, children have to be at risk of abuse, neglect, or institutionalization and there are many, many more children and families that need respite care services than that. The issue of transition is a big one, it is a big one for states. It would be wonderful if we could just fund families, looking at families through the life span and there are some places that are talking about doing demonstration projects and are not limited to age eligibility. Changes are slow and the coordination between children and adult services needs as much attention as the coordination between different children's services.

Question: I am Bill Underwood. I know a lot of you think that all I do is go to conferences, but I want to announce another one at this point. Linda Roebuck and Jay Terry, Linda and Jay are from the state of Missouri, and myself had a drink one night and that was dangerous for us to do. We have now planned what will happen in Kansas City, Missouri, November 30 and December 1 and 2. The first conference is called the Midwest Conference on Family Preservation and it is a marriage of mental health and child welfare. People will be coming to talk about family preservation services. It is also sponsored by Oklahoma, Nebraska, Kansas, Illinois, and Iowa. We did one other thing. We tried to make it very attractive to some high flown people. We went to the Missouri Institute of Psychiatry and they are coordinating the conference so we could have a little bit more along that line. A couple of people who are going to be there are Joy Duva from Child Welfare League of America, Susan Yelton from the Edna McConnell Clark Foundation, so get in touch with the people in your state and try to get them to get at least 12 people from every state represented. We are shooting for 50 percent parents and 50 percent professionals.

EK: We have been talking a lot about advocacy for the last couple of hours. Advocacy individually takes a lot of guts and takes a lot of effort. Advocacy as a community of people is much easier because you can find the support. Creasa mentioned when she was making comments, about an organization that has just been established and I'm not sure it has been mentioned at this conference. If it has, I think it is worth mentioning again. It is called the Federation of Families for Children's Mental Health. There is now a national network of people all across the country who have children with serious emotional disturbances who have come together, not just for advocacy, but for family support and networking of their own. I would like to see how many people here are part of that federation. Could you please stand and identify yourselves so if people want to find out more about this wonderful, exciting new network that is beginning to form. It is for professionals and for families. I would encourage every family member, particularly family members in this room, to contact one of the folks that stood up. It is a wonderful, exciting new effort that is taking place. It will actually get advocacy efforts going. I would like to thank you, you have been a wonderful group of people. Thank you Ted, Liz and Milton for being such dynamic speakers and now I would like to turn the program over to Barbara Friesen.

BARBARA FRIESEN:

Yesterday, I mentioned Katie Yoakum who works at the Portland Research and Training Center and Katie does a lot of different things and really has been the foundation and mainstay of getting this conference prepared. Katie has now typed evaluation forms without benefit of word processor or typewriter eraser. On every table there is a pile of evaluation forms. Please, please fill out the evaluation forms, we really do want to know what you think, we want suggestions for improvements, we want compliments if you want to give them to us. When you are finished you can either leave them on your tables, or better, put them outside on the table.

I just want to repeat, for the state delegations, you now have from 10:15 to 11:45, you will have an hour and a half to finish. Yesterday you should have taken a look at what your state needs or your community, what resources you have and I hope you have also thought about informal resources as well as formal programs. By the end of yesterday, we hope you were able to formulate a few, just two or three goals to work on. Today you have an hour and a half to really sharpen those goals and most of all to develop strategies. Think about how you are going to make this happen. When you have done that, we want you to put a very short report on the overhead transparencies that you have, and I hope that all the facilitators still have their special pens. At lunch time, then we will ask a representative from each state to give a very short report using the overhead projector and so during lunchtime we will just ask the various groups to report to us. We have now a little bit of time for a break, get back into your state delegations.

RESPITE CARE NEED AND RESOURCE ASSESSMENT
Worksheet

Work Session A: Sunday, 3:30-5:00 p.m. (1 1/2 hours)

The purpose of this work session is to think about the respite care needs and the resources that you have in your state or community. What types of respite care are needed the most (e.g., evening child-care, after-school programming, weekend or vacation coverage)? What is already in place (e.g., Are there existing programs that provide services to children with emotional disorders, or might be willing to adapt, with some training)? What types of respite care will be the easiest to develop (e.g., in-home care, care in providers' homes, weekend stays in residential programs, etc.)? What sources of funding are available (including "no-or low-cost" approaches)?

LIST NEEDS BELOW	PRIORITY SCORE

LIST RESOURCES	FUNDING SOURCES

RESPITE CARE STRATEGY DEVELOPMENT
Worksheet

Work Session B: Monday, 10:15-11:45 a.m. (1 1/2 hours)

The purpose of this work session is to develop strategies about how to meet the respite care needs in your state or community. For each strategy, identify (1) what must be done, and (2) who will do it. Strategies developed should be ones that you can carry out, not what you want others to do. For example, a strategy might be to approach the State Mental Health Division to ask that respite care be included as a program improvement in the next budget, and you should identify who will make the approach. Or, you may decide to contact other parents and work to organize a parent cooperative. STATE DELEGATIONS MEMBERS: HOW YOU WILL COMMUNICATE WITH EACH OTHER, AND WHEN YOU WILL MEET AGAIN?

STRATEGIES	WHO WILL DO IT?

Respite Care: A Key Ingredient of Family Support
A National Conference - Covington, KY - October 28-30, 1989

STATE DELEGATION WORK GROUP #1: INDIANA

Needs

1. Attitudes--Focus on family
2. Communications
    - agencies
    - parents
    - public awareness
3. Organizational (access)
    - geographic
    - networking
    - flexibility
    - least restrictive
    - funding

Goals

Attitude Adjustments
    Priority--Preserve family

*Respite available for every parent who needs the service
    o Family focused
    o Least restrictive
    o Community based

Improve communications
    access
    networking

Resources

1. Foster care network
2. Parent support
3. Family subsidy, federal money Crippled Children's, Mental Health, Medicaid, Grants
4. Grandparents program, federal programs (choice)
5. Local programs, day care, Headstart, recreation, etc.
6. Council for Exceptional Children with Behavioral Disorders, IN Assoc. for Mentally Ill, Alliance for Mentally Ill, CASSP, Covolt, P&A, Task Force for Education of the Handicapped, ARC, MHA
7. Portland Center

Goals and Strategies

I. Family Preservation/Community Based Care

A. Consumer involvement
    (education, leadership development, coalition building)--Grass Roots

B. Policy Development--commitment

C. Legislative Change
    (custody, separation, bankruptcy)

D. Technical resources
    - program models
    - knowledgeable personnel

Group #1 - Page 2

II. Locally accessible services to every Indiana family

A. Raise level of community awareness, educate parents regarding respite and other community-based services
  1. State Conference on Respite Care
    - Parents, Foster parents
    - Providers (business meeting separate)
    - Build in opportunity for coalition building (target 8 organizations)

  *from this - advocate for program with legislature
  2. Directory compiled/expand/distribute of existing services

B. Inform potential caregivers/agencies of funding opportunities as become known by state agencies for conferences and respite care

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STATE DELEGATION WORK GROUP #2: KENTUCKY

1. Emergency Respite

   A. *Define emergency respite* (talk to parents; develop specific criteria; develop budget and other specifics)
   B. *Identify providers* (develop pool of providers; utilize other resources, schools, DSS, parents, SNAP parents, foster families)
   C. *Develop parent co-op* (Informal intervention from families; "on-call" families)
   D. *Check funding alternatives*
   E. *Parent's demand local facility* (get to know people to go to; recycle space at night)
   F. *Explore priorities of region* (go to planning/budget meetings 99-660; change/flexible of existing funds)

2. Money!!

   A. Get MA to cover respite. (Lobby; formal process--present specifics; *Squeaky Wheel*; get needed info)
   B. Be creative with MA dollars (specialized programs)
   C. Get private insurance to cover (*Advocacy Effort, Individualized-Case Specific Advocacy*; prove prevention; talk to businesses to sell employee benefit package)
   D. Parent Fee--sliding scale (minimal relating to cost; can't rely on)
   E. Grants
      get important people involved
      get information on grants available
      In-kind contributions
      Be aware of grant audience
      Be positive, persistent, & prepared

3. Networking Among Agencies

   A. Tap into national data sources
   B. See what agencies are doing and build on existing programs
   C. Look at state respite directory and keep it updated
   D. Form task forces, councils, interagency groups
   E. *Meet with people*
   F. *Formulate common ground*
   G. Quarterly Forums
   H. *Form service--specific groups*
   I. *Awareness* (written or computer information, articles, media, etc.)

4. Scheduled Respite

5. Recruitment of Providers

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STATE DELEGATION WORK GROUP #3: OHIO

Goal:

Develop statewide plan encompassing cross-system funding and service provision with flexibility to meet range of family needs.

Strategies:

1) Research what is there and what's needed through a survey or questionnaire
   Who:
   - Determine at next meeting who has resources
2) Define the needs of SED population and families
   Who:
   - This group will develop proposal to ODMH to support this activity
   - This group will position itself to establish a statewide network through federal grant
3) To review model(s)
4) Develop criteria to structure cross-system program and funding mechanisms
   Who:
   - This group
5) Implement

Needs:

1. Statewide plan encompassing cross-system funding and service provision with flexibility to meet range of family needs
2. Advocacy to state legislature with collaboration of advocacy groups and single focus
3. Respite model(s)
4. Parent involvement
5. Training for parents and providers
6. Legal issues

Resources:

1. This group
2. Advocacy groups
3. Existing support groups
4. MH centers
5. Existing models--MR/DD, parenthesis, etc.
6. OCEHC
7. Red Cross/churches

Group #3 - Page 2

8. **$$$$$**
    - CSB
    - fundraising
    - foundations
    - parks/recreation
    - Medicaid
    - private funds
    - education
    - Grants--federal/state/local
    - non-MH organizations
    - research $$ 440

STATE DELEGATION WORK GROUP #4: NEW YORK

Goals:

Education and consciousness raising of public, parents and professionals relating to respite services.

Expansion of 99-660 State Task Force to include respite.

Mandating a respite plan to be included in the discharge plan for children leaving a psychiatric hospital.

Strategies:

Initial education and consciousness raising

- multi-faceted approach: parent newsletters, brochures, parent/professional teams, contacting professionals, parent groups, write legislators, letter to all county MH/CMH directors encouraging the use of respite...

Respite to be part of the State Task Force Agenda

Mandating a respite plan--contact commissioner of MH to mandate respite care at discharge utilizing the Homecare Respite funds.

Needs:

Building advocacy including better publicized services.

Local ownership with more parental involvement in developing services.

Community based services providing easy access.

Resources:

Commitment from OMH--supporting families and developing community based services.

Pilot survey of family needs.

Available funding for respite:
- $300,000 Homecare Respite
- $1 million for family support services
- $6 million DSS

STATE DELEGATION WORK GROUP #5: WEST VIRGINIA

Goal #1

Develop local/state awareness of respite

Strategies:

1) Get people involved in the Office of Consumer Affairs--Trained for Speaker's Bureau
2) Make respite an issue through Parents' Support groups
3) Disseminate information through newsletters of Office of Consumer Affairs and Parents' groups
4) Develop a comprehensive mailing list
5) "Talk up" respite at every opportunity, i.e., workshops, meetings of coordinators
6) Respite re-visit of WV delegation and significant others

Goal #2

Develop a Respite Advisory Board

a) Include a collaborative effort of parents/professionals/advocates
b) Develop a mission statement and workplan (definition, eligibility, needs assessment and evaluation)

Strategies:

1) Respite re-visit of WV delegation and significant other friends of respite
2) Access other state models of organization
3) Approach potential funding sources to support organization of Board
4) Access CASSP for initial incentive funding to get Board going and tap other resources (in-state/out-of-state). CASSP can provide Technical Assistance

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STATE DELEGATION WORK GROUP #6: TENNESSEE

Goals

1) Build statewide advocacy/education network that embraces parents, professionals, providers, public officials and the populace
2) Establish significantly expanded and durable funding base for respite care in state

Strategies

1) Agenda of existing advocacy groups
   Establish new advocacy efforts
   Expand existing respite programs to include families of children with emotional disabilities

2) Substantial changes in Medicaid funding to target respite care
   Work to increase state funding
   Gain access to funding from broad band of non-public sources

Needs

Planning and Development

- o Statewide education effort about respite
- o Advocacy for respite
- o Data regarding current needs, projected needs, and costs
- o More funding support from more sources

Family Service

- o Coordinated and flexible family respite services including:
  - Crisis respite
  - After school
  - Summer day care
  - More trained providers
  - Transportation

Respite Care: A Key Ingredient of Family Support
A National Conference - Covington, KY - October 28-30, 1989

STATE DELEGATIONS WORK GROUP #7: ARIZONA, IDAHO, MONTANA, OREGON, ALASKA and HAWAII

AZ, ID, MT, OR, AK

- *Where are we*: Infancy (conception)
- Goals: Development of Respite as a continuum of service

Motto: AIM AO

Flexible Funding for Flexible Care

Strategies:
1. Information from conference to CASSP directors
2. Needs Assessment specific to state (involve parents)
3. Linkage with child advocacy groups
4. Expand existing successful programs (to include respite)

NO PARENT CO-OP / VOLUNTEERS

HAWAII

Goal: Expansion of current House Bill for Respite Services to include families of SED, DD, cocaine babies, other med. dependant children.
Intro of companion Bill in Senate.
Both Bills to mandate parent and interdepartmental involvement in planning, training, implementation and evaluation.

Strategies:
1. Work with legislator/State cluster support
2. Parent testimony/video development
3. "Coalition" type constituency testimony and support

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STATE DELEGATIONS WORK GROUP #8: ALABAMA, GEORGIA, NORTH CAROLINA, SOUTH CAROLINA and VIRGINIA

Needs:

I. Identify services/resources & target group

- Data collection
- Interagency groups--PL99-457
- Get existing lists of resources in state
- Call Ted Boyden
- Call TRRN
- Get other surveys from other states

II. Funding

- Call Ohio
- Bill Underwood
- Contact businesses/corporations/local civic groups
    - Take advantage of local situations
    - United Way
- State Matching funds
- Build in legislative component to assure longevity of program
- Start small/pilot
- Creative use of existing funding
- Partnership with agencies/advocates

III. Standards

- Don't over regulate
- Contact states that have standards in existence to evaluate
- Use existing criteria already in place in state (DD & MR criteria)
- Use existing agencies
    - Foster care/day care centers, etc.
- Criminal records check
- Use people with child care training
- Family
- Know local regulations

STATE DELEGATIONS WORK GROUP #9: WASHINGTON, D.C., NEW HAMPSHIRE, PENNSYLVANIA, RHODE ISLAND, VERMONT and MAINE

Goals

1. Have a range of respite services which meets parents' needs.

Strategies

All
- State parent organizations as a vehicle for educating parents and professionals about the need for respite services
- Take information back to state and local advisory committees including CASSP and state the need for respite services
- Duplicate and disseminate information to parents including newsletters and parent groups
- Identify and track funding sources at the federal, state and local level and encourage response to PEP's for respite services
- Target funding sources for information and education about the need for respite services

ME
- Continue to include requests for more respite funding in budget presentations to the MH/MR Commissioner

DC
- Education to Central Intake Unit and to program managers in the Child MH System about the use and development of respite services
- Cultivate existing community resources for possible respite services

NH
- Write demo grant and share with other states for the next round

STATE DELEGATIONS WORK GROUP #10: IOWA, ILLINOIS, MINNESOTA MICHIGAN and SOUTH DAKOTA

IOWA

1. Promote idea of respite as an entitlement program for special needs populations among state planners.
2. Advocate for respite development in conjunction with other services such as family preservation and aftercare.
3. Advocate for more state coordination of respite services and resources.

Barry Bennett

ILLINOIS

- Reeducate Illinois programs about respite
- Promote parent support and advisory groups
- Pursue information from other model programs
- Explore additional local, state and federal monies for respite service development

MINNESOTA

Develop a consciousness for respite services based on the diverse needs of community family support.

Sheila Morinville
Deb Jones

MICHIGAN

Objectives:

- Develop a State Directory
- Hold a "Meeting of the Minds" in Michigan
- Explore CASSP funding

Group #10 - Page 2

SOUTH DAKOTA

1. Awareness of Respite:
   Sharing of the information and ideas re: what we've learned in regards to what Respite Care is, what it can be and what it is not.
2. In those areas of the state that do have somewhat of a "rainbow of services," we would like to incorporate respite care. This would help to show its effectiveness.
3. Ensure that respite care providers are trained to care for kids who display emotional disturbance.

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STATE DELEGATIONS WORK GROUP #11: KANSAS, MISSOURI and NEBRASKA

KANSAS

Goals

1. Establish statewide services
2. Stabilize funding sources
3. Train more quality providers

Implementation Strategy

1. Support new legislation (without modification)
2. Monitor legislative process
3. Lobby for statewide implementation

MISSOURI

Strategies:

1. Present need, resource assessment and funding alternatives to state CASSP and PL 99-660 Workgroup
2. Inform the parents who are involved in the 2 respite care programs in the state about CASSP network
3. Target groups of parents and professionals who may wish to be involved in advocacy through two parent/professional conferences
4. Place article in CASSP newsletter about respite and questionnaire on other respite services.

Needs:

1. State assessment
2. Reinforce family support services as model system of care
3. Unite children's advocacy groups in supporting the system of care
4. Explore funding availability
5. Explore "O" reject model for children who have an SED

Resources	Funding Sources
Parents	Federal grants
CMHC's	Medicaid waiver
Residential txt centers	State funding
DMH/DESE/DFS/DYS	Foundations
University students	Donations
	Industrial

NEBRASKA

Goals and Needs

1 a. Determine number of parents of children (0-21) with handicaps (include children with SED/BD) that would like respite services and the array of options needed (e.g., in-home, out-of-home, etc.).
  b. Determine why parents have not made use of existing United Way respite services program (e.g., financing, accessibility, skill level of providers, etc.).

2. Get approval from Hastings Respite Care Board to expand current program to a component that focuses specifically on services for children with behavioral difficulties.

3. Develop and implement training program for providers which will provide them with skills to serve children with behavioral difficulties.

4. Locate respite care providers which can serve families in rural areas.

5. Locate funding sources to support the cost of the respite care providers (e.g., salary, mileage).

6. Develop State Plan for respite in the context of a larger array of family support services.

7 a. Define ways to make public aware of respite services available for families.
  b. Define ways to build community understanding of children with behavioral difficulties.

Strategies

1 a. Develop and conduct survey.
  b. Use survey results to improve existing program and expand service and training options.

2. Advisory Council meet with Hastings Respite Care Coordinator.

3 a. Gather and review Kansas curriculum;
  b. Ask South Central to conduct training;

c. Incorporate materials into on-going respite care training program. Involve Hastings College students in developing the curriculum.

4. Establish cooperative program with Hasting College (as part of college practicum) to utilize college students as respite care providers for children with behavioral difficulties in rural areas.

5. Appoint committee to develop directory of array of funding service options.

6. Develop State Respite Care Network and hold Family Support Service Conference.

7 a. Develop and distribute brochure of respite care services.
b. Develop and present multi-media information regarding children with behavioral difficulties. Meet with church and other civic groups.

Resources

1 a. See what state has done;
b. View sample surveys from Kentucky and MCRI.

3. Existing respite care program has baseline training and structure to provide skills for serving children and adults with behavioral difficulties. Gather additional training resources geared for children with behavioral difficulties.

4. Existing respite care program continue to advertise for providers.

5. Parents can financially support the service to a limited degree (e.g., sliding scale, $1-2 per hour) but need additional financial sources and array of financial support options tailored to individual needs of families.

6. Family Policy Department and NDE Interagency Policy Team.

7 a. Existing respite care brochure and Texas brochure (as a model).
b. Hasting College student develop media package. Develop speakers bureau.

Funding Sources

CASSP; In-kind; United Way; and DSS.

STATE DELEGATIONS WORK GROUP #12: ARKANSAS, LOUISIANA, OKLAHOMA and TEXAS

ARKANSAS

- Mandated entity to coordinate respite services
- Independent Case Management
- Empowering Families
  - Education
  - Families As Allies
  - Support Groups

LOUISIANA

- Report on this conference to State, CASSP Committee and Region 1, 10 & 7 teams
- Identify existing respite services
- Determine needs for crisis nurseries and varied respite services

OKLAHOMA

- Inter-agency coordination
- Educate--community,
  professionals,
  families
- Co-op rural areas

TEXAS

- Statewide Task Force on Respite Care (TX Respite)

- Empower Families through education

- Work on systems change--go after more Medicaid dollars

STATE DELEGATION WORK GROUP #13: FLORIDA

1) Develop Strategies
    - a. Implement family services planning teams
    - b. Identify existing sources of funding for respite services
    - c. Identify service providers
    - d. Identify priority group to be served and needs
    - e. Develop family support groups
    - f. Identify priority respite service i.e., in-home, out-of-home, etc.
    - g. Identify training resources i.e., community colleges, mental health centers, etc.
    - h. Identify community resources i.e., volunteer agencies, YMCA's, churches, health clubs, Boy Scouts, etc.
    - i. Keep services flexible

2) Identify Needs
    - a. After school/weekend services
    - b. Community awareness
    - c. Multi-agency involvement
    - d. Family/community-based philosophy

3) Identify Resources
    - a. Therapeutic foster parents
    - b. Crisis shelters
    - c. Private providers
    - d. University students and professors
    - e. PIC, chamber of commerce

4) Goals
    - a. There will be respite services in every district in Florida by June 30, 1991

RESPITE CARE: A KEY INGREDIENT OF FAMILY SUPPORT

PRESENTERS AND MODERATORS

Introduction and Welcome

Barbara J. Friesen
Director, Research and Training Center on
Family Support and Children's Mental Health
Portland State University

Catherine Staib
Parent
Frankfort, Kentucky

Plenary Panel: Respite Care: A Key Ingredient of Family Support

Terry Butler
Connections Coordinator
Multnomah County Social Services Division
Portland, Oregon

Barbara Huff, President
Keys to Networking
Topeka, Kansas

Creasa Reed, Parent Consultant
Department of Mental Health
Frankfort, Kentucky

Judith Sturtevant, Parent/Consultant
Department of Mental Health
Waterbury, Vermont

Moderator: Ellen Kagan,
Assistant Director for Technical Assistance
CASSP Technical Assistance Center
Georgetown University Child Development Center
Washington, D.C.

Workshops

Number	Offered	Description
A-1	a.m.	**"Natural Allies" Respite and Parent Support Groups** Joyce Aaron, Respite Care Program Services Coordinator, Gateway Association, Inc., Anderson, Indiana Meredith Adler, Program Consultant, Center for Mental Health, Anderson, Indiana

A-2	a.m.	**Mental Health Family Respite Care - A Model Project** Milton Cassady, Information and Referral Specialist, Texas Respite Resource Network, San Antonio, Texas Elizabeth Newhouse, Assistant Director, Texas Respite Network, San Antonio, Texas
A-3	a.m.	**Respite is a Family Matter** Louise Barnes, Regional Coordinator, Tennessee Department of Mental Health and Mental Retardation, Nashville, Tennessee Wade McCurdy, Respite Coordination Services, Nashville, Tennessee Matthew Timm, Executive Director, Regional Intervention Program, Nashville, Tennessee Carol Chatman, Parent, Regional Coordination Services, Nashville, Tennessee
A-4	p.m.	**Halcyon Respite** Thalia Forist, Executive Director, Halcyon Respite, Grand Rapids, Michigan David Jinkins, President, Board of Director, Halcyon Respite, Grant Rapid, Michigan
A-5	p.m.	**Rural Respite Care: From Model to Program** J. Michael Geary, Crisis Intervention Specialist, Department of Mental Health, Charleston, West Virginia David Majic, CASSP, Department of Mental Health, Charleston, West Virginia
A-6	p.m.	**"The Break Away" Respite Program"** Creasa Reed, Parent Consultant, Department of Mental Health, Frankfort, Kentucky Melissa Runyan, Program Coordinator, Bluegrass West Comprehensive Care Center, Georgetown, Kentucky
A-7	p.m.	**The Vermont Respite Care Demonstration Project** Judith Sturtevant, Parent/Consultant, Department of Mental Health, Waterbury, Vermont

		Mary Carol Masseneau, Howard Mental Health Center, Burlington, Vermont
B-1 & B-3	am & pm	**Rest A Bit: Respite Care Training for Families of Children with Emotional Problems** Richard Donner, Assistant Professor, Washburn University, Topeka, Kansas Barbara Huff, Executive Director, Keys for Networking, Topeka, Kansas
B-2	a.m.	**Why Re-Invent The Wheel? How to Preview and Select Instructional Materials, To Adopt or Adapt, that Will Meet Your Training Needs** Phyllis Tarrent, State Department of Vocational and Technical Education, Stillwater, Oklahoma
B-4	p.m.	**Training for Respite Care Providers** Joyce Aaron, Respite Care Program Services, Gateway Association, Inc., Anderson, Indiana
C-1 & C-2	am & pm	**Financing Respite Services** Ted Boyden, GAO Evaluator, U.S. General Accounting Office, Detroit, Michigan Bill Underwood, Manager, Behavioral Treatment Unit, Division of Children and Family Services, Little Rock, Arkansas
D-1 & D-3	am & pm	**Building Advocacy for Respite Care: The Maine Model** Susan Failing, Coordinator, Bureau of Children with Special Needs, Bangor, Maine
D-2	a.m.	**Parents Creating Respite Services** Judith Wagner, Center of Handicapper Affairs, Lansing, Michigan
D-4	p.m.	**How to Start a Respite Program** Milton Cassady, Information and Referral Specialist, Texas Respite Resource Network, San Antonio, Texas Elizabeth Newhouse, Assistant Director, Texas Respite Network, San Antonio, Texas

Luncheon Address

Richard Donner, Assistant Professor
Washburn University
Topeka, Kansas

Plenary Panel: Respite Care: The National Perspective

Ted Boyden, GAO Evaluator
U.S. General Accounting Office
Detroit, Michigan

Milton Cassady, Information and Referral Specialist
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San Antonio, Texas

Elizabeth Newhouse, Assistant Director
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SUMMARY

As these materials demonstrate, the Respite Care Conference took steps toward successfully addressing its primary objectives. The "Plenary Panel on Respite Care: A Key Ingredient of Family Support" helped set the tone for much of the work that occurred during the rest of the conference. Subsequent speakers, panelists and workshop leaders provided conference participants with both thought-provoking commentary and with ideas which they can adapt to their own situations.

INFORMATION ABOUT CONCEPTS, PROGRAMS, AND ISSUES

Respite care concepts, issues, and programs were explored. Respite care services have been developed for families who have members with a variety of disabilities. There are few programs developed especially for families whose children have emotional or behavioral disorders. Participants learned how successful programs that serve other disability groups can be adapted to serve families of this particular population. All conference participants were aware that there are special areas of concern when respite programs work with families of children who have difficult behavioral problems. It was a positive experience for parents who attended the conference to hear that there were others who had developed and implemented services to meet their unique needs. Professionals were encouraged to listen to the concerns of family members when developing and implementing respite care services.

DESIGNING, FINANCING, AND IMPLEMENTING PROGRAMS

The workshops covered a variety of issues. There was general agreement about the need for respite care services as part of a larger program of family support. Concerns addressed in workshops included how to finance these services, how to best train respite care providers, how to pull together diverse elements in a community to advocate for respite care services, and how to actually design and implement a program.

CONFERENCE OUTCOMES

State delegations generated action plans and strategies for implementation upon returning to their home states and communities. Planned activities include efforts to coordinate various interest groups, to raise the awareness in local communities, to develop advisory boards composed of parents, professionals, and other advocates, to collect data on costs, liability, training, and insurance, to lobby state legislatures for funds and reasonable standards, and to identify needs of parents in local communities.

Some delegations made very definitive plans to implement in their home communities. Indiana CASSP and Respite Care Programs are sponsoring a statewide conference March 17, 1990, *Respite Connections: Building a Frame for Family Support*. The participants from New York plan to make respite part of the State Task Force Agenda. Delegates from West Virginia plan to meet regularly and recruit others to their group. Participants from Hawaii plan to lobby for expansion of a current House Bill for Respite Services to include families of children who have emotional disorders. They also plan to introduce a companion bill in the Senate in Hawaii. Nebraska delegates plan to conduct a survey of parents to determine the need for respite care services and the types of services they prefer. The Florida group set a goal of having respite care services in every district in Florida by June 30, 1991.

CONCLUSION

The effects of the conference are just beginning. The conference provided new insights and information for both parents and professionals. Participants affirmed their commitment to providing the best possible services for families who have children with emotional or behavioral disorders. The conference stimulated individual activities as well as provided the impetus for planning activities at the community and state levels.

These conference proceedings may be useful to others planning to organize similar conferences designed to explore respite care and other family support services. This conference was a gratifying experience for Research and Training Center staff; we urge others interested in family support services for families with children who have emotional or behavioral problems to explore ways to bring parents and professionals together. Within a forum that encourages open and frank discussion, family members and professionals can form alliances that can be useful in improving services for children with emotional disorders and their families.

RESEARCH AND TRAINIG CENTER ON FAMILY SUPPORT AND CHILDREN'S MENTAL HEALTH

National Respite Conference

Evaluation Form

29 Parent   102 Professional   2 Other

1. Opening Plenary Session *Parent Panel*

This session was (circle one)

1	2	3	4
Very Useful	Useful	Somewhat useful	Not at all useful
43 (53%)	28 (36%)	6 (8%)	1 (1%)

Comments: ____________________

____

2. Sunday Morning Workshops

Workshop Session attended ____________________

This session was: (check one)

- _____ This was new information; I need to learn more abut it before I can apply it to the situation in my community/state.
- _____ This was exactly what I needed; I can apply it right away.
- _____ I knew this information already, but it was a useful refresher.
- _____ I knew this information already; I learned nothing new.

3. Sunday Luncheon Speaker *Richard Donner*

This session was (circle one)

1	2	3	4
Very Useful	Useful	Somewhat useful	Not at all useful
36 (44%)	40 (49%)	4 (5%)	2 (2%)

Comments: ____________________

____

4. Sunday Afternoon Workshops

Workshop Session attended: ____________________

This session was: (check one)

- _____ This was new information; I need to learn more abut it before I can apply it to the situation in my community/state.
- _____ This was exactly what I needed; I can apply it right away.
- _____ I knew this information already, but it was a useful refresher.
- _____ I knew this information already; I learned nothing new.

5. State Delegation workgroups *Need and Resource Inventory*

Session attended: ______________________________

1	2	3	4
Very Useful	Useful	Somewhat useful	Not at all useful
19 (24%)	30 (38%)	27 (34%)	4(5%)

6. Resource Exchange Reception

1	2	3	4
Very Useful	Useful	Somewhat useful	Not at all useful
19 (27%)	22 (31%)	27 (38%)	3 (4%)

7. Monday Morning Panel *National Perspective*

1	2	3	4
Very Useful	Useful	Somewhat useful	Not at all useful
41 (53%)	28 (36%)	8 (10%)	1 (1%)

8. State Delegation Workgroups *Strategy Development*

Session attended: ______________________________

1	2	3	4
Very Useful	Useful	Somewhat useful	Not at all useful
13 (21%)	28 (44%)	13 (21%)	9 (14%)

9. Conference Accommodations

	1	2	3	4
	Excellent	Good	Fair	Poor
Rooms	40 (52%)	32 (42%)	4 (5%)	1 (1%)
Hotel Staff (Assistance and courtesy)	34 (45%)	34 (45%)	7 (9%)	1 (1%)
Food	20 (25%)	47 (59%)	10 (13%)	3 (4%)

Comments: ____

10. Recommendations for future conference: ______________________________

____

____

____

ADDITIONAL RESOURCES

Publications:

1. United States General Accounting Office (1990). *Respite Care: An Overview of Federal, Selected State, and Private Programs.* GAO/HRO-90-125.

The first five copies of each GAO report are free. Additional copies are $2.00 each from:

U.S. General Accounting Office
P.O. Box 6015
Gaitersburg, MD 20877
(202) 275-6241

2. Stroul, B. & Friedman, R. (1986). *A System of Care for Severely Emotionally Disturbed Children and Youth.*

Order through:

Georgetown University Child
Development Center
3800 Reservoir Road, N.W.
Washington, DC 20007
(202) 687-8837

3. *Respite Care: A Guide for Parents.* (1991)
Respite Care Is for Families: A Guide to Program Development. (1991)

Each book costs $4.00
Order through:

CSR, Incorporated
Respite
1400 Eye Street, NW #680
Washington, DC 20005
(202) 842-7600

4. Butler, T.E. & Friesen, B.J. (1988). *Respite Care: An Annotated Bibliography.*

(see ordering address below).

5. Butler, T.E. & Friesen, B.J. (1988). *Respite Care: A Monograph.*

Order through:

Research and Training Center on
Family Support and Children's
Mental Health
Regional Research Institute for
Human Services
Portland State University
PO Box 751
Portland, OR 97207
(503) 725-4040

OTHER:

1. CASSP Technical Assistance
   Georgetown University
   2233 Wisconsin Ave., NW
   Washington, DC 20007
   (202) 338-1831

2. Research and Training Center for
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   Florida Mental Health Institute
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3. Research and Training Center on
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Respite Care: A Key
Ingredient of Family Support

EVALUATION FORM

1. Who used the conference proceedings? (Check all that apply.)

___Parent ___Educator ___Child Welfare Worker

___Juvenile Justice Worker ___Mental Health Professional

Other (Please Specify)______________________________

2. Please describe the purpose(s) for which you used the proceedings:

____

____

3. Would you recommend use of the conference proceedings to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments:__________________________________

4. Overall, I thought the conference proceedings were: (Circle one)

Excellent Average Poor

Comments:__________________________________

5. Please offere suggesions for the improvement of subsequent editions of these conference proceedings:

____

____

____

____

We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

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